Exploring young people's experiences following a diagnosis of ADHD

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Contents

Word count

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Thesis overview	307	-	307
Literature review	6,660	1,444	8,104
Research paper	8,374	1,331	9,705
Appendices	8,417	-	8,417
Total	**23,758**		

Thesis overview

Attention Deficit Hyperactivity Disorder (ADHD) is the most common childhood mental health diagnosis, with estimates of prevalence continually increasing. However very little research has explored young people's experiences of their diagnosis and treatment, despite adolescence being a critical period for development. This thesis synthesises and extends the existing qualitative research undertaken with adolescents diagnosed with ADHD regarding their life experiences following diagnosis. It particularly focuses upon the impact of 'being diagnosed with' and 'medicated for' ADHD. Two papers comprise this thesis: a systematic literature review and an original research paper, which are briefly described below.

The systematic literature review was prepared for submission to Emotional and Behavioural Difficulties. It utilised systematic search strategies and conducted a thematic synthesis to identify and synthesise the existing qualitative literature on the experiences of adolescents diagnosed with ADHD. Eleven papers were eligible for inclusion in the review and each was appraised for methodological quality. Five analytical themes were identified: Differing perspectives of the problem; Societal pressures; Sense of self; Feelings about medication; and Maturational shift from passive to active. The findings are discussed in terms of culture and identity, and the need to highlight strengths and autonomy is emphasised.

The empirical paper was prepared for submission to Clinical Child Psychology and Psychiatry. It used a grounded theory approach with eleven adolescent participants (aged 16-18 years old) who had been diagnosed when they were aged between 8 and 13 years old. This paper focused on young people's identity development and how this was impacted by their diagnosis and treatment. A comprehensive theoretical model of the findings was constructed, which visually depicted participants' transitions through seven distinct stages, which each

had profound implications for their identity. These findings were discussed in relation to the factors involved in the development of a healthy identity, and the value of diagnosis and treatment was critically considered.

Adolescent experiences of living with a diagnosis of ADHD: A systematic review and thematic synthesis

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Laura Eccleston is a Trainee Clinical Psychologist at the University of Liverpool. This work formed the major research component of her Doctorate in Clinical Psychology, supervised by James Williams, Laura Soulsby and Sue Knowles.

Prepared for submission to Emotional and Behavioural Difficulties[1]

[1] The manuscript was prepared in line with author guidelines for Emotional and Behavioural Difficulties (see Appendix 1). The word count for this journal is 8000 words, inclusive of tables, references, figure captions, footnotes and endnotes. Chicago Manual of Style 16th Edition (author – date) referencing is used.

Adolescent experiences of living with a diagnosis of ADHD: A systematic review and thematic synthesis

Seeking young people's perspectives is integral to delivering effective mental health care. This systematic review aimed to synthesise the qualitative research exploring the life experiences of young people diagnosed with ADHD. Four electronic databases (CINAHL, MEDLINE, PsycInfo and SCOPUS) were searched in February 2017 for peer-reviewed, qualitative English language studies exploring the perspectives of adolescents formally diagnosed with ADHD. Eleven studies were included and appraised for methodological quality and a thematic synthesis was undertaken. Participants' stories highlighted both positives and challenges within five analytical themes: Differing perspectives of the problem, Societal pressures, Sense of self, Feelings about medication, and Maturational shift from passive to active. The findings suggested that interpersonal conflict, stigma, and invalidation have a negative psychological impact upon young people's self-esteem and identity. Support strategies are needed to maximise adolescents' resilience, autonomy and abilities.

Keywords: ADHD, adolescent, systematic review, qualitative synthesis, diagnosis

Introduction

ADHD is the most common mental health diagnosis in children and the most frequent reason for their referral to services (Polanczyk et al. 2014; Singh 2011; Varley 2011). Children diagnosed with ADHD experience lower mood, higher anxiety, and greater academic difficulty than those without the diagnosis (Bagwell et al. 2001; Birchwood and Daley 2012; Johnston and Mash 2001; Wehmeier, Schacht, and Barkley 2010). They also face heightened stigma and have poorer quality interactions with family members and peers (Bringewatt 2011; O'Driscoll et al. 2012). These problems may be amplified during adolescence, a critical period for internal and interpersonal conflict, transitions, and identity formation, where there are increasing expectations of independence and complex social functioning (Erikson 1993; Williamson, Koro-Ljungberg, and Bussing 2009; Wolraich et al. 2005).

Medication remains the most common treatment for ADHD, with its use increasing by 800% between 1995 and 2015 (Renoux et al. 2016), although the value of non-pharmacological interventions (e.g. parenting interventions, Cognitive Behaviour Therapy [CBT], social skills) has been emphasised recently (Moore et al. 2016; NICE 2016). Previously ADHD was considered a problem confined to childhood. However, these problems are now thought to persist beyond adolescence and new UK guidelines recommend the continued identification and treatment of ADHD into adulthood (NICE 2016). Despite this, most adolescents discontinue their medication by the time they turn 21 years, leaving them with little alternative support (McCarthy et al. 2009; NICE 2016). Given the need for person-centred cost-effective care, the increasing prevalence of ADHD and lack of effective intervention is concerning. Exploring adolescents' perspectives is essential to evaluate the helpfulness of service provision and ensure that resource is directed most effectively (Singh et al. 2010).

Gaining young people's perspectives

Whilst quantitative methodology is important, it fails to adequately examine young people's thoughts and concerns (Kendall 1997; Varley 2011). This is integral for good clinical practice and can lead to new insights and improvements in service provision (Department of Health 2015; Varley 2011). Although there remains a paucity of qualitative in comparison to quantitative research, an increasing number of studies have explored young people's experiences of ADHD and its treatment (e.g. Bringewatt 2011; Brinkman et al. 2012; Gallichan and Curle 2008; Krueger and Kendall 2001; Singh et al. 2010; Singh 2011). Two recent reviews have synthesised the qualitative literature regarding school-based interventions for ADHD (Gwernan-Jones et al. 2016; Moore et al. 2016). These were narrow in focus and incorporated views from parents, teachers and professionals. As yet, no systematic review has synthesised the findings from studies exclusively exploring adolescents' experiences. Such a review may lead to new insights and clinical implications for the diagnosis and intervention of ADHD within the adolescent population.

Approach to synthesis

Thematic synthesis (Thomas and Harden 2008) offers a transparent method and a high level of analytical abstraction from the primary studies to contribute new understandings of participants' perspectives, and was the chosen method for this review. This review addressed the question, 'How do adolescents experience different aspects of life following a diagnosis of ADHD?'

Method

A protocol for this review was registered with the PROSPERO database for systematic reviews (CRD42017057838). PRISMA guidelines for conducting and reporting systematic reviews were followed (Moher et al. 2009).

Search strategy

Search terms were formulated using the SPIDER tool (Cooke, Smith, and Booth 2012). Thesaurus tools (e.g. Medical Subject Headings [MeSH]) were utilised to identify relevant terms within each database (Table 1). Literature searches took place in February 2017. The following databases were searched: CINAHL, MEDLINE, PsycInfo and SCOPUS (Appendix 2). The Cochrane Library, Campbell Collaborations and PROSPERO were searched to identify existing or anticipated relevant reviews. Key journals were hand searched (ADHD Attention Deficit and Hyperactivity Disorders, Child and Adolescent Mental Health, Emotional and Behavioural Difficulties, Journal of Attention Disorders, Journal of Child Psychology and Psychiatry) and cited references in eligible articles and key review articles were reviewed. Mendeley reference management software was used to organise the articles and support the screening process.

Table 1. SPIDER tool for the identification of search terms

Domain		Search terms
S	Sample	"Young person", child*, adolescent, "young man", "young woman", girl, boy, youth
Pi	Phenomenon of interest	ADHD, "attention deficit hyperactivity disorder", "attention deficit disorder with hyperactivity", "attention deficit disorder"
D	Design	Qualitative, "grounded theory", "interpretative phenomenological analysis", IPA, "thematic analysis", "content analysis", "narrative analysis", interview*, "focus groups"
E	Evaluation	Experiences, expectations, opinions, stories, narratives, "life experiences"

Inclusion and exclusion criteria

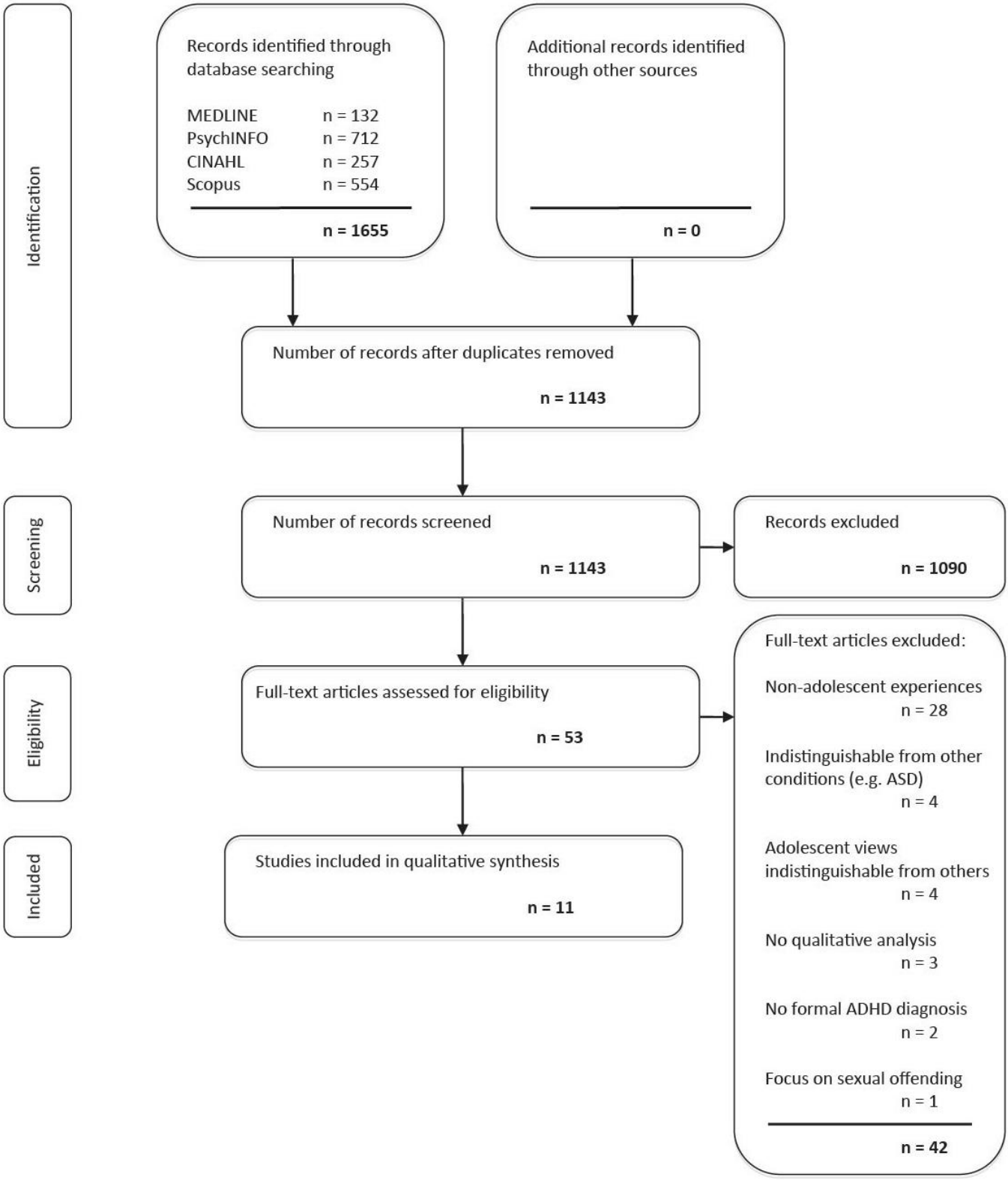
The following inclusion criteria were applied: (a) papers written in or translated into English; (b) papers exploring the narratives and views of adolescents (aged 13-18) diagnosed with ADHD; (c) papers where all participants had been formally diagnosed with ADHD; (d) papers utilising qualitative methods of data collection and analysis; (e) peer reviewed, primary research (Appendix 3).

Papers were excluded if adolescent narratives could not be distinguished from those of others (e.g. due to some participants being outside the adolescent age-range, or having differing diagnoses to ADHD [e.g. learning disability, autistic spectrum disorder] or being unable to distinguish between dyads [e.g. with parents or professionals]). Papers were excluded if they did not directly explore experiences relating to their diagnosis (e.g. teacher strategies, transition into adult services). Unpublished theses, book chapters, non-peer reviewed journal articles, reviews, commentaries and opinion pieces were excluded due to them not having been subject to the scrutiny of peer-review. No date restrictions were applied.

Study selection

The search yielded 1655 articles (PsychInfo, 712; SCOPUS, 554; CINAHL, 257; MEDLINE, 132). LE applied the inclusion/exclusion criteria and identified 11 studies that were eligible for synthesis (Figure 1). A colleague of LE selected 10% of articles to screen at both title/abstract and full text stages, and applied the inclusion/exclusion criteria to each of the 11 selected full texts to confirm eligibility. There were no disagreements in the decisions made for these samples.

Figure 1. Flow diagram showing identification of papers.



Quality assessment

Criteria developed by Walsh and Downe (2006) were used to appraise the quality of included studies. This checklist contained 12 criteria spanning eight stages of the research process (e.g. scope and purpose, design, sampling, analysis). One point was awarded for each criterion that was described sufficiently within the paper. A ½ point was introduced to differentiate between studies that 'sufficiently' and 'insufficiently' met the prompts contained within each criterion (Appendix 4). Higher scores reflected greater methodological quality, with a maximum score of 12. LE and a colleague assessed the studies independently and any discrepancies were resolved through discussion. Quality appraisal was undertaken to contextualise the ensuing synthesis (Appendix 5).

Data extraction and synthesis

The Joanna Briggs Institute Quality Assessment and Review Instrument (JBI-QARI: The Joanna Briggs Institute, 2014) was used to extract descriptive data (Table 2). A thematic approach was used to synthesise the findings (Thomas and Harden 2008). This technique adopts methods from meta-ethnography and grounded theory to develop descriptive and interpretative analytical themes that aim to 'go beyond' the primary studies and generate new constructs, hypotheses or explanations. Within this method, all text labelled as 'results' or 'findings', was considered 'data' for abstraction. Full-text PDF documents were entered into QSR's NVivo 10 for Mac software for qualitative data analysis. Where text PDF files were not available, results sections were retyped verbatim into the software.

There were three stages to the synthesis (Appendix 6). First, data were coded line-by-line to capture the meaning and content of each sentence. All data, whether author defined codes or original participant quotes were treated as raw data for coding. Most sentences had several codes applied and were structured hierarchically where possible. Concepts were translated between studies by applying existing codes or creating new concepts. LE examined the codes for similarities and differences to refine the coding hierarchy, which aided identification of descriptive themes. Finally these themes were grouped and discussed, which led to the development of analytical themes. LE completed all stages of the analysis, facilitated by discussions with SK and LS.

Results

Five over-arching themes regarding participants' life experiences following a diagnosis of ADHD were identified: 1) Differing perspectives of the problem (a physical condition, academic disadvantage, part of my personality, behaviour and emotions, and being normal) 2) Societal pressures (stigma and rejection, others' expectations, and conflict and invalidation), 3) Sense of self (feeling different, needing acceptance, affected self-esteem, and maintained versus altered identity), 4) Feelings about medication (efficacy, burden, and weighing up the costs and benefits) and 5) Maturational shift from passive to active (shifting role of adolescent, scaffolding through support, and worry about the future). Distribution of these themes across each of the 11 studies is shown in Table 3. Illustrative quotations are shown in Table 4.

Table 2. Data extraction table for included studies

Author(s) Year	Method	Phenomena	Setting	Geography	Culture	Participants & sampling method	Analysis	Conclusions	Quality assessment score
Avisar and Lavie-Ajayi 2014	Semi-structured interviews lasting approx. 45mins	Experiences of ADHD and stimulant medication	Clinic or participant home	Israel	Developed country Mainstream education	14 adolescents (8 boys, 6 girls) 12.5-16.5 years old Convenience sampling	IPA	Helpfulness of medication is on a spectrum	10/12
Brinkman et al. 2012	Semi-structured, focus groups lasting approx. 1.5 hours	Experiences of decision making regarding medication and impact of ADHD on creativity and driving	Medical centre	USA	White and African American Developed country	44 adolescents 13-18 years old Purposive sampling (stratified by gender and age)	Inductive qualitative method	Adolescents assume an increasing role in managing medication and could benefit from support	9.5/12
Charach et al 2014	Semi-structured interviews 60-90 minutes long	Beliefs and attitudes regarding use of stimulant medication	Participant home or clinic	Canada	Developed country Average intelligence, no psychiatric diagnosis	12 adolescents 12-15 years old Purposive sampling (stratified by gender and age)	Interpretive interactionist framework	Views of adolescents may differ from their parents and impact on medication use	9.5/12

Gibbs, Mercer, and Carrington 2016	Semi-structured interviews and focus groups, analysis of academic school reports Length not stated	Schooling experience of boys	Not stated	Queensland, Australia	Independent boys school	Six boys aged 15-16 years old Convenience sample	Distillation or constant comparison	Taking medication, receiving support surrounding friendships and learning, and adapting classroom environment important	11/12
Hallberg et al. 2010	Semi-structured interviews Length not stated	Experiences of ADHD treatment and consequences of diagnosis and treatment	School, home or office of interviewer	Norway and Sweden	Rural and suburban	10 adolescents (5 male, 5 female) aged 13-18 years old	Grounded theory	Adolescents strive for normalcy and conceal diagnosis and treatment from others	10/12
Knipp 2006	Semi-structured interviews Length not stated	Perceptions of ADHD and medication	Home of participant	Arizona, USA	Upper middle class public school	15 adolescents aged 14-17 years old	Content analysis using a priori conceptual categories	Medications are helpful. Finding right medication and dose is important	7.5/12
Koro-Ljungberg et al. 2008	Qualitative experience sampling method (ESM) over 3 months, using mobile phones for critical incidents	African-Americans' descriptions of their life with ADHD	Naturalistic settings	Southern USA	African-American	Four adolescents (2 female, 2 male) aged 13-15 years old	Narrative analysis	Investigation of teen personalised realities aids quality of communication	11/12

Krueger and Kendall 2001	Two semi-structured interviews with each participant 1-2 hours long	Experiences, perceptions and ways of managing ADHD	Not stated	North Western USA	Middle income, professional families, one low income family, 7 in two-parent homes, 4 in single mother homes	11 adolescents (8 males, 3 females) 13-19 years old	Constant comparative method	Adolescents' sense of self is distorted, therapy needs to develop sense of self	11/12
Levanon-Erez et al. 2017	Semi-structured interview using 'Occupational Performance History Interview' (V2.1) 1 – 2 hours long	Occupational identities of adolescents with ADHD	Private room in clinic or own home	Jerusalem, Israel	Hebrew (translated transcripts)	10 adolescents (8 males, 2 females) 12 – 17 years old	Directed content analysis	Adolescents face occupational identity challenges and may need occupational therapy to remedy	9/12
Sikirica et al. 2015	Semi-structured interviews 30 – 60 mins long	Unmet needs of adolescents with ADHD and carers	Telephone – conducted in native language	Europe (France, Germany, Italy, Netherlands, Norway, Spain, Sweden and UK)	43% attending behaviour therapy	28 adolescents (14 male, 14 female) Aged 13-17 years old Convenience sample	Content and thematic analysis	Unmet needs of adolescents and caregivers persist despite treatment (e.g. school and interactions)	11/12

Weiner and Daniels 2016	Semi-structured interviews 2 hrs – 3 hr 15 min long, plus one follow up interview with each participant 2 – 4 mths later	School experiences of adolescents	Average intelligence	Canada	Developed country	12 adolescents (9 boys, 3 girls) Aged 14-16 years old	Modified grounded theory	Difficulties with organisation and academic performance Teachers understand nature of disorder and provide monitoring and scaffolding required,	9/12

Table 3. Distribution of descriptive and analytical theme

Analytical and descriptive themes	References											
	Avisar and Lavie-Ajayi 2014	Brinkman et al. 2012	Charach et al. 2014	Gibbs et al. 2016	Hallberg et al. 2010	Knipp 2006	Koro-Ljungberg et al. 2008	Kendall and Krueger 2001	Levanon-Erez et al. 2017	Sikirica et al. 2015	Daniels 2016	Wiener and
Differing perspectives on the problem												
Medical: A physical condition called ADHD	X	X	X		X	X	X	X		X		
Part of my personality		X	X			X	X	X	X	X		X
Academic disadvantage	X	X				X	X		X	X		X
I'm normal	X	X	X			X	X	X	X			
Behaviour and emotions		X					X	X	X	X		X
Societal pressures												
Experiencing stigma and rejection		X		X	X			X	X	X		X
Others' expectations	X	X	X				X	X	X	X		X
Conflict and invalidation	X	X	X			X	X	X		X		X
Sense of self												
Feeling different	X	X	X	X	X	X	X	X	X	X		X
Needing acceptance		X	X	X	X	X	X	X	X	X		X
Affected self esteem		X	X	X	X	X	X	X	X	X		X
Maintained vs altered identity	X	X	X		X	X		X		X		
Feelings about medication												
Treatment efficacy	X	X	X	X	X	X				X		
Treatment burden	X	X	X	X	X	X				X		
Weighing up the costs and benefits	X	X	X							X		
Empowerment												
Scaffolding through support	X	X		X	X		X	X		X		X
Maturational shift from passive to active	X	X	X		X		X	X	X	X		X

Table 4. Table of quotes reflecting descriptive themes

Analytical and descriptive themes	*Participants' quotations* and/or authors' explanations
Differing perspectives on the problem	
Medical: A physical condition called ADHD	'*I see ADHD as a disability'* Four youth understood it to be a disorder or illness that 'happened' to them All participants explicitly stated that if they could choose freely they would not want to have a neuropsychiatric diagnosis (such as ADHD) owing to shame associated with psychiatric diseases.
Part of my personality	*'If I didn't have ADHD, I don't think I'd be me…'cause if I didn't have ADHD I'd bet you I'd be totally different.'* *'Its just a part of me kind of, its who I am.'* These youth experienced symptoms and behaviours associated with ADHD as unique personality characteristics and a part of their self-identity, rather than as impairments.
Academic disadvantage	'*I think I'm stupid and I don't understand my schoolwork.'* '*Last year I was at [a school with a high academic level] and I was kicked out because I couldn't keep up, I knew all the material but I had this ADD thing.'* Adolescents often reported schoolwork difficulties (96%).
I'm normal	*'I am not different, just with more energy (laughing).'* *'I don't see myself any different than anybody else.'* *'Its not difficult…I don't have a difficulty; its up to what I want. If I want to concentrate I will.'*
Behaviour and emotions	Sharonne noted that she had a bad attitude and lost her temper easily. *'I always try to get them [beat them up] before they get to me.'* Disciplinary problems resulted from behaviours such as fighting, talking at inappropriate times, not finishing tasks, inattention, getting to class late, missing school, and verbal aggression.
Societal pressures	
Experiencing stigma and rejection	*'My (sister) calls me ADHD freak.'* *'You got ADHD? I really don't want to get to know you.'* Sadly, but not surprisingly, every student described having been bullied at one point or another during his or her school career.
Others' expectations	Their core being, their sense of who they were, was disrupted only in relation to the developmental expectations society held for them. *'Like I'm always told to just sit still, stop fidgeting, pay attention and its like, most of the time I can, but, like, I cant help it sometimes.'* *'If people can't handle me, that's their problem. I get tired of other people's expectations.'*

Analytical and descriptive themes	*Participants' quotations* and/or authors' explanations
Conflict and invalidation	One interviewee clearly stated that she felt that she was not taken seriously by the professionals and that bothered her. Many interviewees describe their struggle to be heard. *'My mum didn't listen to me at all. I had to take it.'*
Sense of self	
Feeling different	*'(Medicine) made me different. It made me all calm and quiet and stuff and I don't like that. I like to be wild.'* *'I am more different from a lot of people because I take pills and have more problems'* Before they had received their diagnosis, when they were younger, they had not at all thought about themselves as deviating from normalcy or being different from others their age. But after receiving the diagnosis of ADHD they began to think about themselves as deviant.
Needing acceptance	*'You have to fit in otherwise you get teased and everything because you don't have friends.'* The teenagers strove for normalcy and wanted to be like everyone else. His story conveyed the importance and value he placed on belonging to his peer group.
Affected self esteem	The narratives of the adolescents above reflected the threat of their condition on their sense of competence. One teen felt that he was unique with a special gift. *'I've had pretty negative thoughts about myself and ADHD since I was little, especially when people are nagging me about things when I mess up. I try to do things right, but I can't. I think it's the way I'll always be.'*
Maintained versus altered identity	*'You feel like you are in your own world when you take Ritalin, as if you are in a bubble. People talk to you and you really…it is really different…It was shocking! It wasn't me. It was as if someone took a syringe and injected it into me; that's how I felt.'* *'When you're off the medicine that is the only time you can really be you.'* Approximately half the youth voiced concerns about the medication changing who they are.
Feelings about medication	
Treatment efficacy	Half of the interviewees reported that the medication helped them to concentrate during exams…on the other hand, the other half of the interviewees described the medication as disrupting their efforts to study. *'I haven't taken Ritalin for 4 years because I don't think it helps.'* *'I definitely get my work done. It [the medication] sort of makes me feel like more of a normal student.'*

Analytical and descriptive themes	*Participants' quotations* and/or authors' explanations
Treatment burden	*'I was sitting in class just like that, even more tired, not thinking about anything. I wouldn't eat; with the Ritalin I would play football as if I was drunk. I was less hungry and tired with no desire to do anything.'* Most of the interviewees discussed the difficulties of taking medication especially in terms of emotional side effects, identity loss, and interpersonal relationships. Some described feeling *'like a robot'* only interested in completing schoolwork.
Weighing up the costs and benefits	With the medication, Yair feels that he has to give up his joy of life for the ability to learn. *'I'd say it was a good and bad experience. (My mom) liked that I was doing good in school but at the same time, at home she didn't like the way I was acting. I wasn't myself.'* *'I was just able to focus more, but (medication) has its defects. You are tired, you are sleepy, you get headaches and all of that. But overall the good outweighs the bad.'*
Maturational shift from passive to active	
Shifting role of adolescent	The transformation from the passive voice at the beginning of the trajectory, *'The teachers have recommended that my parents take me to be diagnosed,'* to the active voice at the end of the trajectory, *'I just stopped cause of the way it affected me.'* *'I have more decisions. Its more up to me than it was before.'* Responsibility for treatment decisions is transferred from parent to adolescent over time.
Scaffolding through support	Teenagers described parental involvement in medication taking that ranged from providing direct supervision, to reminders, to providing no supervision. Most of the adolescents suggested that, since they entered high school their parents have become less involved in their education. *'Certain qualities that teachers have in their teaching helps me to learn.'*
Worry about the future	Future was expressed as vague and hopeless. They described themselves as constantly 'messing up' and disappointing others. They expressed little hope of doing better in the future. *'Without (my mum) my everyday life wouldn't work out, she's the most important person in my life. I'm not sure how things will be in the future, when I have to move away from home.'* Many adolescents expressed doubt and uncertainty about their future use of medication.

Theme 1: Differing perspectives of the problem

The first analytical theme reflected participants' various understandings of their problems. These often differed from those of their peers, parents, teachers and healthcare professionals.

Medical: A physical condition called ADHD

Some participants believed that ADHD was an illness, disorder or disability, which was responsible for their difficulties. This perspective was reinforced by the diagnostic and treatment process, where participants were given a diagnostic 'test' and informed by a medical expert that they had ADHD. The treatment offered was then almost exclusively medication. Participants described having very little involvement in diagnostic or treatment decisions. This was the predominant understanding held by teachers, professionals and family members.

Part of my personality

Most participants considered ADHD to be a personal characteristic that comprised part of their identity; 'it's who I am'. Thus they often did not consider behaviours or 'symptoms' to be impairments. Some participants reported that ADHD gave them strengths (e.g. energetic, fun, creative, outgoing, talkative, funny) and said that they 'liked' these aspects of their personality, despite them also posing difficulties for them.

Academic disadvantage

ADHD was discussed as an academic disadvantage in all but two papers. Accordingly medication was believed to enable concentration so that participants could complete schoolwork and tests. Most young people described struggling academically in comparison to their peers and found schoolwork boring, too difficult or too fast-paced.

Behaviour and emotions

In eight papers, participants described expressing their emotions physically or verbally either through anger and frustration (e.g. aggression, violence or failing to comply), becoming tearful and upset, or from withdrawing from others or avoiding situations (e.g. procrastination).

I'm normal

Some participants did not differentiate themselves from their peers and did not identify themselves as having a difficulty. Rather, they saw others' expectations as the problem, not their own.

Theme 2: Societal pressures

Participants described the pressure they experienced to 'fit in' with societal rules and expectations. They did not feel their 'uniqueness' was valued, appreciated or accepted.

Others' expectations

Participants reported that others expected them to be able to perform well at school, by remaining focussed and interested in their lessons and completing homework. This resulted in participants either internalising the importance of academic success, or actively rejecting it. One study reported gender differences; girls internalised others' expectations and felt inadequate and boys defended against them with bravado. Medication use was assumed rather than considered a choice. Often participants reported feeling forced to continue taking medication by their parents or doctors.

Experiencing stigma and rejection

Participants commonly experienced conflict, bullying and rejection. Sometimes this was severe and had a lasting impact on their identity and self-esteem. Participants recognised and feared stigma, and often hid their diagnosis or medication from others so they were not treated differently. Participants also described feeling rejected by teachers who viewed them as 'troublemakers' due to their diagnosis. As above, one paper identified gender differences in participant responses to stigma; boys utilised bravado to protect their identity and self-esteem, whereas girls internalised the sense of difference, failure and inadequacy.

Conflict and invalidation

Participants found that their views and opinions were dismissed and rejected, particularly where they opposed the views of people in a position of relative power such as their parents, professionals or teachers. They described feeling invalidated and treated as though they were too young to understand. For example, participants did not feel the burden of taking medication was recognised, despite the side effects being severe. One participant pleaded with her mother, 'Try taking it, feel what I'm feeling, a disgusting feeling.' Participants wished to be taken seriously and have their knowledge of their experiences acknowledged. Where this did not happen, participants remained in conflict with others and became 'non-compliant'.

Theme 3: Sense of self

Feeling different

Participants reported that they had difficulty making and sustaining friendships and felt different and inadequate to their peers, particularly following their diagnosis. Young people described feeling they needed to hide their diagnosis and medication so they did not appear ‘abnormal’ or get bullied. Whilst some young people felt embarrassed or ashamed of their diagnosis or medication, others did not feel different or describe experiencing stigma. Some participants even felt unique, ‘special’ and gifted because of ADHD. Others said the medication made them feel ‘more normal’ and competent.

Needing acceptance

Due to their feelings of difference, participants strove to be liked and accepted and tried hard to please others. One paper found girls placed more importance on meeting the expectations of others and being accepted than boys.

Affected self-esteem

Some participants described having positive self-esteem and emphasised their strengths and talents. For other participants, their aforementioned inability to meet the expectations of others and ‘do things right’ resulted in low self-esteem, characterised by a sense of incompetence, failure and inadequacy.

Maintained versus altered identity

Several papers found that approximately half the participants felt their identity was altered by the medication; they felt alien and experienced identity loss. This loss appeared temporary, and their true self was rediscovered when they were not taking medication. Other participants described their identity remaining unchanged by the medication.

Theme 4: Feelings about medication

It was evident that although some participants found the medication helpful, they all experienced its negative effects.

Treatment efficacy

Approximately half of the young people interviewed found the medication helpful. Helpfulness was almost exclusively discussed in terms of academic performance. One participant described how the medication helped her with her relationships, however this was discussed in terms of generalised social withdrawal. The remaining participants did not find medication helpful, and some reported that their schoolwork worsened due to the medication making them more tired and less motivated. They noted that their being subdued was helpful for their teachers and fellow students, even if not for themselves.

Treatment burden

Participants reported severe physical side effects including loss of appetite, weight loss, dizziness, headaches, stomachaches, nausea, tiredness, and loss of energy. A few

participants reported that they had become accustomed to these side effects and no longer experienced them.

Participants felt the emotional side effects of medication were much worse. These included feeling numb, subdued, irritable, and losing motivation or desire to socialise or engage in activities they previously enjoyed. This resulted in feelings of a 'lost self' and affected their interpersonal relationships. They also described feeling depressed.

Weighing up the costs and benefits

Participants described their dilemma of weighing up the benefits of medication for their schoolwork, against the treatment burden described above. Participants' desire to discontinue medication was a consistent theme throughout the papers.

Theme 5: Maturational shift from passive to active

Shifting role of the adolescent

Four papers described in detail the shifting role of the adolescent from being a passive recipient of instruction from others, to being an active collaborator or even being autonomous in decisions regarding their medication use or schooling. In some cases this meant young people stopped their medication with or without telling their parents or began using the medication more selectively to achieve goals (e.g. in school). This appeared to be related to age/maturity, and greater knowledge or awareness of ADHD, treatment and future consequences.

Scaffolding through support

When they were first diagnosed, participants described decisions being taken for them by 'experts' such as their parents, teachers and professionals. They found that being supported and empowered enabled them to take more of an active role and emphasised the importance of being acknowledged, understood, validated and taken seriously. They wanted to understand the range of different intervention options so they could receive support that best met their needs. Finally they highlighted teaching strategies that were helpful at engaging them in lessons, for example enforcing boundaries that have clear instructions and consequences, and having smaller, quieter classes.

Worry about the future

Some participants felt the future was unpredictable and insecure, due to their perceived inadequacy and being less competent than their peers. They worried about finding a partner or succeeding well enough in their education to obtain a meaningful job. They also worried about living alone without the continued support of their parents.

Participants continued to worry about their future use of medication, which they did not want to continue taking for their life's duration. Some were concerned that they would be unable to cope at work without medication, whereas others felt that being apart from their friends would allow them to concentrate.

Discussion

This systematic review synthesised the data from 11 primary research studies (166 participants) across 12 Western countries regarding participants' life experiences following a diagnosis of ADHD. Participants' stories highlighted both the positives and

challenges of their experience within five analytical themes: 1) Differing perspectives of the problem, 2) Societal pressures, 3) Sense of self, 4) Feelings about medication, and 5) Maturational shift from passive to active. The synthesis offered new insights into participants' struggle when their own perspectives and experiences conflicted with those of their family, professionals and peers, and the impact of this upon their relationships, self-esteem, and developing identity. It described how participants coped with these challenges through gradually transitioning from a passive to active role, becoming more autonomous and utilising the support of others. These detailed accounts from adolescents strengthen the argument for the increasing emphasis on shared decision-making and active engagement of young people in their care and service development, and ought to inform diagnosis and intervention pathways for ADHD (Department of Health 2015; Mental Health Taskforce 2016).

Young people's understanding of ADHD varied. Many participants considered the 'symptoms' of ADHD core aspects of their personality. Indeed some participants did not identify these 'symptoms' as 'problems' and instead considered their energy or ADHD positive aspects of their character. Others felt the diagnosis reflected a very specific difficulty (e.g. academic, social skills, behaviour, and emotions), with schoolwork the most significant difficulty causing distress. Participants described coping with this distress through avoidance (e.g. procrastination, distraction, withdrawal) or expressing it through their behaviour (e.g. crying, physically or verbally lashing out). Many young people felt these difficulties could be overcome with support or a shift in expectations (Gallichan and Curle 2008; Koro-Ljungberg et al. 2008; Krueger and Kendall 2001; Williamson et al. 2009). It is important to recognise that whilst Western society values high academic success, not all students will find themselves adept at this task and instead may embody alternative strengths (Wiener and

Daniels 2016). Gallichan and Curle (2008) referred to the mismatch between expectation and ability as 'fitting square pegs into round holes' and noticed that their participants did not experience difficulty where the 'hole' (i.e. environment) adapted to the 'peg' (i.e. the child). Therefore, young people's understanding of ADHD appeared to be influenced by their socio-cultural context and inability to meet various societal expectations. Their understandings mostly contrasted with the homogenous 'medicalised' perspectives taken by professionals and often their parents, who considered ADHD a medical condition requiring medication, a view to which some young people also ascribed. This range of perspectives reflects the wider controversy and debate in the literature surrounding whether ADHD is a medical or socially constructed phenomenon (Singh 2002, 2008, 2012; Timimi 2010; Timimi and Radcliffe 2005).

This may explain some young people's dislike of medication, due to its effect upon their identity. The studies within this review consistently found low self-esteem, feelings of difference, and identity loss, and these findings have been consistent across other qualitative studies with children and young people diagnosed with ADHD (Bringewatt 2013; Gallichan and Curle 2008; Loe and Cuttino 2008; Singh et al. 2010). Stigma, bullying and rejection were also common experiences and arose from participants being identified as 'different'. Given that adolescence is a critical period for peer relationships, conflict and identity formation, these findings are particularly significant (Erikson 1993).

Some participants described positive experiences of medication, whereby they 'got used to' side effects and appreciated the benefits medication provided. Other young people consistently perceived that the side effects outweighed the benefits. The extent of physical and emotional side effects caused by ADHD medication is a consistent

finding across the qualitative quantitative literature (Avisar and Lavie-Ajayi 2014; Brinkman et al. 2012; Charach et al. 2014; Knipp 2006). This suggests that the prevalence and severity of side effects is significantly higher than quantitative research suggests (e.g. Efron, Jarman, and Barker 1997; Graham et al. 2011). However, often participants' experiences and feelings were not discussed, which resulted in conflict, invalidation and frustration for the young person and their parents. Occasionally this meant that parents and adolescents were working at cross-purposes, whereby the adolescents hid their decision to stop taking medication while their parents pressured them to take it (Avisar and Lavie-Ajayi 2014; Brinkman et al. 2012). This indicated a failure by health professionals to recognise and address adolescents' reported difficulties surrounding side effects, identity loss, decreasing self-esteem or interpersonal conflict during their assessment or interventions, which contradicts current guidance (Department of Health 2015; Mental Health Taskforce 2016). This review emphasized the importance of validation, support, empowerment and autonomy for participants. Indeed, participants may be unable to reach a state of independence without feeling empowered to take a valued self-management role in their intervention (Lorig and Holman 2003).

Implications for practice

Adolescents' widely varying perspectives on ADHD highlighted the unique meaning of the diagnosis to each of them and emphasised the importance of hearing and attempting to understand these perspectives as part of the diagnostic and intervention process. Despite best practice guidance, it was clear from the reviews that young people were not considered equal decision-makers or valued contributors to plans surrounding diagnosis and intervention. This had profound effects upon their psychosocial wellbeing and self-

esteem. Indeed it could be argued that many of the young people in this study were not consenting to their treatment, despite demonstrating Gillick Competence (Cornock 2007). Instead, parental and professional perspectives were emphasised. The trajectory of adolescents from passive to active was gradual, however often participants described having to hide their differences of opinion or decisions not to take medication from their parents and professionals for fear of invalidation or repercussion. Feeling empowered to be an active participator in making choices about their own care was validating and enabled participants to become active agents. This corroborates existing guidance that suggests that shared decision-making increases active involvement, self-management and confidence (Department of Health 2015; Mental Health Taskforce 2016). In addition to assessing and incorporating the views of children and young people of *all* ages, professionals ought to assess Gillick competence as the young person grows older. Individual capacity ought to be enhanced through the provision of information and discussion with the young person. Where Gillick competence is demonstrated, it is essential that the young person's decision be upheld.

This review highlights the importance of receiving support, which is consistent with NICE (2016) guidance for intervention. However, very little attention was given to psychosocial interventions within the research, so the extent to which these are routinely offered is unclear. Participants described appreciating structure that allowed for flexibility, boundaries, engagement, and feeling accepted and validated. However, due to their experience of stigma, any additional support needed to minimise feelings of 'difference' and not appear punitive or pathologising. In addition to acknowledging, validating and supporting difficulties, professionals should also highlight the adolescent's unique strengths, resources and talents.

Strengths and limitations

There were a limited number of studies eligible for inclusion into the synthesis, therefore any conclusions drawn need to be considered within this context and remain tentative hypotheses for further exploration. However, despite the differing epistemological or reflexive positions of the researchers in each study, the themes generated were relatively homogenous, enhancing the trustworthiness and applicability of the findings. Most studies were published within the last 10 years, reflecting both their relevance and the paucity of qualitative research in this field. A greater yield may have been gained through including grey literature within the search. However, this may have affected the quality ratings of included studies, as they would not have been assessed through the peer-reviewing process.

The review adhered to PRISMA guidelines for reporting systematic reviews (Moher et al. 2009). Finally, it highlighted the importance of undertaking such research to ensure that the adolescent's voice is heard amongst the dominant 'expert' narrative, in line with best practice and current policy guidance in the UK (Department of Health 2015; Mental Health Taskforce 2016).

Quality rating

The value of assessing quality in qualitative research is subject to ongoing debate, and the notion that qualitative research can be methodologically flawed is contested. Rather than exclude studies based on their quality rating, we used Walsh and Downe's (2006) appraisal criteria to critique the included studies in order to contextualise the thematic synthesis. All studies scored above 7.5 out of 10 reflecting good methodological quality. Most had a clear rationale, research design, used an appropriate method, and grounded

their conclusions in the data. However, only one study commented on researcher reflexivity and many did not discuss ethical implications, despite these being considered core aspects of qualitative research.

Future research

Following this review, several areas warrant further investigation. All of the existing research took place in Western, individualistic cultures. Future research ought to explore understandings of 'hyperactivity', 'impulsivity' and 'inattentiveness' in other cultures. Even within Western cultures, greater diversity of ethnicity, religion and social class would enhance our understanding of how different social groups interpret these experiences.

Quantitative research should explore young peoples experiences of medication side effects further, since their perspectives are currently underrepresented.

It is clear that the development of adolescent identity is disrupted following a diagnosis of ADHD. However, it remains unclear how and why adolescents experience and adjust to their diagnosis and medication differently. Further qualitative research is needed to explore young people's identity transitions, to ensure clinical practice is most helpful for their psychological wellbeing.

Conclusions

ADHD is a common mental health diagnosis in children and young people that has significant implications for adolescents' physical and emotional wellbeing and sense of self. Acknowledging and validating young peoples' experiences and adopting a collaborative and empowering approach to intervention can protect against the psychological impact of medication and stigma. Strategies that aim to maximise

adolescents' resilience, autonomy and abilities are needed to facilitate healthy identity development and self-esteem in young people diagnosed with ADHD.

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A qualitative study into the impact of an ADHD diagnosis upon self-identity and personal relationships in adolescents

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Abstract

Young people diagnosed with ADHD have described experiencing a distorted sense of self and low self-esteem. Using a grounded theory framework, this study aimed to develop a theoretical model of the processes involved in identity formation following a diagnosis of ADHD. Semi-structured interviews were completed with 11 adolescents aged 16-18 years regarding the impact of their diagnosis and treatment upon their identity. Participants described their personal characteristics (including strengths) being reframed as 'symptoms', which led them to question their identity. Medication either compounded young people's 'loss of self' or enabled them to become a 'better version of self' by suppressing their difficulties. Maturational processes promoted shifts in identity that aligned more with accepted cultural norms. A healthy identity was achieved when the adolescent felt valued, accepted and empowered. These findings have significant implications for healthcare and educational providers regarding diagnosis and intervention for ADHD.

Keywords

ADHD, identity, self-esteem, grounded theory, adolescent

Introduction

ADHD is the most diagnosed and medically treated mental health problem in children throughout the world (Polanczyk, Willcutt, Salum, Kieling, & Roude, 2014; Singh, 2011). Estimates of UK prevalence doubled between 2003 and 2008, and latest figures range between 7-9% (McCarthy et al., 2012; Polanczyk et al 2014). Consequently, prescriptions for ADHD medication increased by 800% between 1995 and 2015 (Renoux, Shin, Dell'Aniello, Fergusson, & Suissa, 2016).

Despite the increasing prevalence rates, ADHD remains a controversial diagnosis. The ambiguity of core symptoms, lack of international diagnostic consistency and increase in the use of prescribed medication make the diagnosis a key sociological and ethical topic, and its validity as a distinct 'medical' disorder continues to be disputed (Singh, 2002, 2008, 2012, Timimi, 2010, 2011; Timimi & Radcliffe, 2005).

Understandings of ADHD range from those that adopt a biomedical position and believe ADHD is a 'brain disorder', to those that take a social constructivist stance and argue that ADHD reflects a child's failure to meet societal expectations (NICE, 2016; Singh, 2002; Timimi & Taylor, 2004). These competing frameworks are prominent within the media, impacting upon societal understandings (Hennessy & Heary, 2009; Sutcliffe, 2015). Thus, it is important to understand how this impacts upon children developing with this diagnosis.

Existing research

A plethora of quantitative research has examined the cause, definition, and treatment of ADHD (Sibley, Kuriyan, Evans, Waxmonsky, & Smith, 2014; Sonuga-Barke et al., 2013; Wolraich et al., 2005). The diagnosis is associated with a range of negative outcomes including low mood, academic difficulties, anger and anxiety, low

self-esteem, and interpersonal problems, including bullying and rejection (Bagwell, Molina, Pelham, & Hoza, 2001; Birchwood & Daley, 2012; Wolraich et al., 2005). Historically, it was thought that ADHD existed only in childhood. Now these difficulties are argued to persist, and the continued identification and treatment of ADHD into adulthood is recommended (NICE, 2016). Given the negative outcomes and limited effect of existing interventions (e.g. medication, cognitive behavior therapy (CBT)), there is a need for greater contextual understanding of young people's experiences of ADHD to inform clinical practice (Kendall, 1997; Singh, 2012).

Existing qualitative research: Young people's perspectives

Exploring the views of young people allows us to learn from those with lived experience to inform treatments and service development (Department of Health, 2015; Faulconbridge, Law, & Laffan, 2015; Macleod et al., 2017; Mental Health Taskforce, 2016; Varley, 2011). Research shows that young people hold varying understandings of ADHD, including: a medical condition or disability; an academic deficit; a conduct or emotional disorder; an aspect of their personality; or 'normal' (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach, Yeung, Volpe, Goodale, & Dosreis, 2014; Knipp, 2006; Sikirica et al., 2015; Wiener & Daniels, 2016), which inform their beliefs regarding medication (Singh, 2012). For example, where ADHD was viewed as an emotional disorder, medication was believed to improve emotional regulation.

Gallichan and Curle (2008) found that young people's understandings of ADHD related to their failure to meet the expectations of their given context. The 12 young people interviewed described striving to become a 'good person', and saw medication as a means to become more socially acceptable. This was referred to metaphorically as, 'trying to fit square pegs in round holes', and was seen to create a vicious cycle, leading to feelings of rejection, inadequacy, loss of control and low self-esteem. The opposite

effect was noticed where the environment was more flexible, as this fostered a sense of agency and a positive sense of self. Therefore, feelings of empowerment or disempowerment were determined by context and were key in shaping participants' future experiences.

Participants' narratives of treatment decisions also featured a consistent theme of disempowerment. There was a lack of collaboration in exploring the costs and benefits of medication compared to other forms of intervention, and despite young people's protests of significant physical and emotional side effects, parents and professionals did not consider medication treatment to be a choice (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014; Knipp, 2006; Singh, 2012). This led young people to feel passive, disempowered and invalidated (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014). During later adolescence, adolescents' narratives suggested their autonomy and independence improved. However, their continued fear of being dismissed meant they kept their decisions regarding medication hidden, which may have left them feeling increasingly alienated from their support-network (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012).

Stigma was another common theme, linked to feelings of rejection and low self-esteem (Hallberg, Klingberg, Setsaa, & Moller, 2010; Krueger & Kendall, 2001). Hallberg et al. (2010) interviewed 10 adolescents who described feeling the need to hide their ADHD diagnosis and medication from others, in order to 'fit in' and be 'normal'. The participants in Krueger and Kendall's (2001) study did not feel ADHD was an 'illness' needing 'fixing', but considered it part of their core personality. This led them to internalize their experiences of stigma and 'difference', which resulted in feelings of shame, inadequacy and 'badness'.

ADHD and identity

Identity disruption emerges as a consistent theme across the studies, highlighting the significance of this social process for individuals diagnosed with ADHD. Young people may have developed a sense of self as 'bad' or different to others (Hallberg et al., 2010; Krueger & Kendall, 2001). This is consistent with modified labelling theory (e.g. Link 1987), which argues that labelling a child with a mental health diagnosis places them in a separate cultural category (i.e. 'mentally disordered'), and leads to societal expectations and beliefs regarding a 'mentally disordered' child (e.g. 'bad', 'wrong', 'ill', 'naughty'). This may affect the child's identity and relationships with others. Diagnosis can medicalise both the problem and the child, reducing consideration of social and cultural explanations of their behaviour (Allan & Harwood, 2013, Kroska & Haakness, 2008).

As a diagnosis, ADHD differs to those of traditional 'illnesses' as it does not imply that there has been a change in the individual. Instead, it labels something that has always been part of the person's identity, similar to Autism Spectrum Disorder (ASD) or Intellectual Disability (ID). Hence the 'symptoms' of ADHD are integral to young people's identity and characterize who they are (Krueger & Kendall, 2001). This may explain the consistent finding that medication negatively distorts adolescents' sense of self, since it suppresses these characteristics (Avisar & Lavie-Ajayi, 2014). Singh (2012) interviewed 150 children across the UK and USA to examine the social and ethical impact of ADHD diagnosis and treatment. Younger children (aged 9 years), and participants experiencing significant side effects, reported a 'loss of self' resulting from medication. Conversely, some children described gaining a 'second personality' (an additional, enhanced personality housed within their authentic 'self') whilst taking medication, which did not affect their identity.

The current study

Whilst identity issues have been recognized, there is a need for a deeper understanding of the nature and impact of this disruption. The current study aimed to extend the existing literature by constructing an explanatory theoretical model of identity development. Grounded theory enables us to consider the various abstract concepts and specify the relationships between them, in order to more fully understand the processes involved in participants' experiences.

Adolescence is a critical period for navigating internal and interpersonal conflict, transitions, increasing independence, and identity formation (Erikson, 1993; Williamson, Koro-Ljungberg, & Bussing, 2009). Thus exploring the retrospective accounts of older adolescents would be particularly valuable, and allow a detailed examination of the various dynamic factors and their relative contribution over time.

Method

Design

This research aimed to develop a detailed theoretical understanding of the social processes involved by going beyond the content of participants' data. Thus Charmaz's (2014) approach to grounded theory was used. This takes a constructivist epistemological position and views the emerging theory as a composition of researchers' and participants' interpretative understandings, interactions, and shared meanings, rather an objective reality. The researchers held a symbolic interactionist perspective, which makes the assumption that the self is constructed through relations with the external world (Charmaz, 1983). This allowed for examination of changes in the self, following the incorporation of 'ADHD'. It was assumed that the individual would draw upon past experiences, cultural meanings and knowledge to engage in a

mental dialogue about the meaning and definitions underlying their social existence.

Input from service users

Members of the Liverpool Experts by Experience (LExE) group and an adolescent service user expert were consulted during the beginning stages of the research. The procedures, documents and interview guide were adapted following their feedback. As interviews progressed, feedback was sought from each participant, which shaped subsequent procedure.

Ethics

The local NHS Research Ethics Committee, the Health Research Authority, and local research and development departments at four NHS sites approved this study (Appendix 8).

Recruitment

Participants were recruited from three NHS Child and Adolescent Mental Health Services (CAMHS), a specialist community paediatric service, several colleges, charities, and support groups, and social media. Adverts (Appendix 9) were placed in waiting rooms in each service. Clinicians distributed fliers to young people who met the inclusion criteria when they attended CAMHS. Alternatively clinicians contacted young people or their parents (if the young person was not available) via phone or letter to see if they were willing for the researcher to contact them. LE contacted those that consented by telephone for an informal discussion about the study, before asking whether they would like to take part. Five adolescents whose parents had given initial

consent withdrew from the study, stating that they felt too ‘anxious’, ‘awkward’ or ‘busy’. Participants were given a £10 voucher to reimburse them for their time.

Participants and sampling

Eleven young people (eight males, three females) aged between 16 years 2 months and 18 years 5 months were interviewed between July 2016 and April 2017. All participants had been given a formal diagnosis of ADHD from a suitably qualified health professional when they were aged 8 – 13 years old. This age period was chosen so that participants had memory and awareness of the diagnostic process and life before it, and provided sufficient time for reflection on how life had changed since (at least three years). Participants were excluded if they had diagnoses of ASD or ID because of associated confounding factors. Due to the reliance on spoken language and the potential for discussion of sensitive content, only participants able to communicate in English who were deemed to be psychologically robust enough to talk about their experiences were accepted into the study.

The first four participants represented a convenience sample. Subsequent participants were sampled theoretically to further explore emerging relationships between participants’ narratives and their gender, geographic location and medication use. All participants resided with family and nine had multiple siblings. Demographic information is displayed in Table 1. All names are pseudonyms.

Table 1. Demographic information for participants

Name	Age (years)	Age of diagnosis (years)	Time since diagnosis (years)	Currently medication use
Lee	16	9	7	Yes - Helpful
Leanne	18	13	5	Yes - Helpful
Jamie	16	10	6	Yes - When needed
Matthew	18	12	6	Yes - Helpful
Sian	16	8	8	No
Andrew	18	13	5	No
Rebecca	16	10	6	Yes - Not helpful
Derek	16	12	4	Yes - When needed
Josh	17	8	9	Yes - Not helpful
Mark	16	8	8	No
Tony	16	12	4	No

The interviews

Participants were interviewed alone to ensure confidentiality and allow full freedom of expression. Before beginning the interview, participants were given an information sheet (Appendix 10) and had the opportunity to ask questions before signing a consent form (Appendix 11). Demographic details were taken using a brief questionnaire (Appendix 12). Interviews were recorded by digital voice recorder and lasted between 28 and 69 minutes. Each participant was interviewed once using a semi-structured topic guide (Appendix 14 and 15), which was designed to focus on their self- and other-defined identity chronologically as they developed through adolescence (e.g. "How would you describe yourself?" or "How would others describe you?"). The interviews adopted a curious approach; learning from participants as experts of their own experiences. The interview guide developed over the course of the interviews, to explore relationships between emerging themes. LE and JW critically reviewed the transcripts to refine the interviewing technique.

Reflexivity

At the beginning of the study, LE made a reflexive statement (Appendix 13) regarding her thoughts and expectations regarding the research to ensure these did not influence either data collection or analysis. Reflexivity was discussed regularly through supervision and supported with detailed memos.

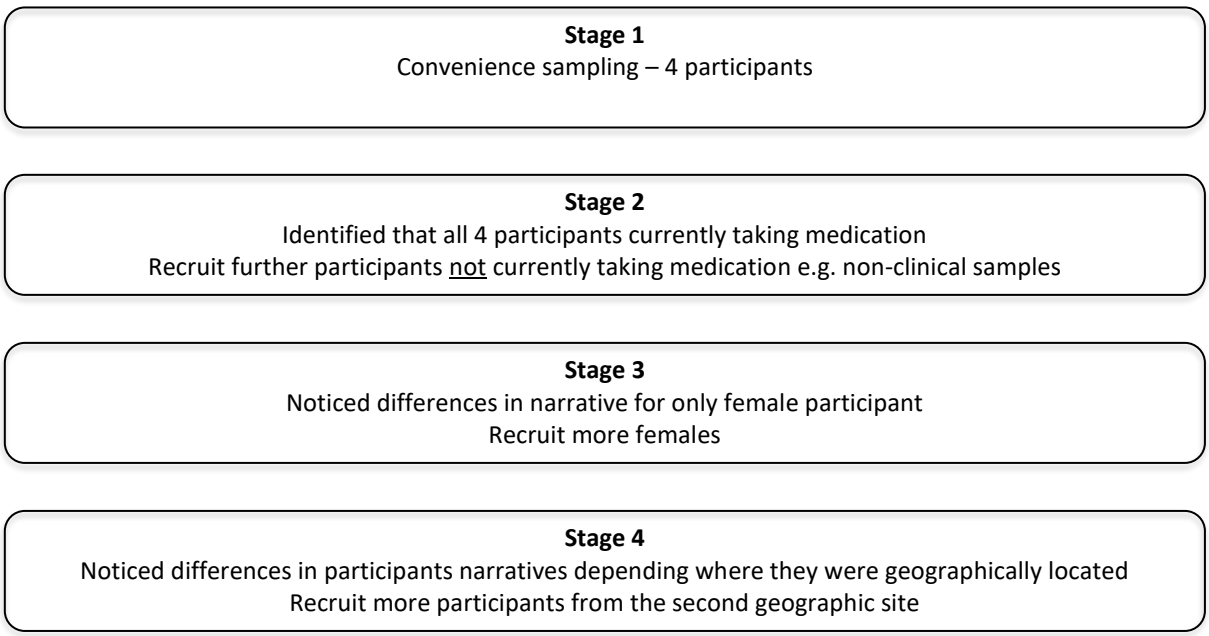
Analysis

Analysis was conducted in two stages using a grounded theory approach (Charmaz, 2014). Interviews were transcribed and coded as they were completed prior to the next interview. Following each interview, LE wrote detailed memos and reflective notes to capture initial thoughts, highlight pertinent codes, emerging theory, future questions, provide a narrative and diagrammatic summary, and a critique of questioning style (Appendix 16).

Stage 1. LE transcribed the first four interviews so she was fully immersed in the data. Each interview was coded line-by-line then re-read to identify codes at a higher level of abstraction that might represent focused or theoretical codes. Subsequent interviews were coded using existing codes and new codes were developed as necessary, yielding 740 initial codes in total. This process was reflexive and as new codes emerged, former transcripts were recoded. Further memos compared, contrasted and synthesised initial codes into focused codes, which included: prior experience; support; stigma; medication; maturation; and self-development. Overall, 263 focused codes were identified and organised hierarchically under 11 conceptual categories (Appendix 17). These findings were used to adapt the interview guide for the second stage and identify directions for theoretical sampling (e.g. participants not taking medication, females, varying geographic location). The theoretical sampling process is described in Figure 1.

Stage 2. Seven further interviews were completed and transcribed. Focused coding was undertaken and revised wherever data did not fit existing codes. No new codes were identified after interview seven and the final four interviews were used to confirm and refine analytical understanding. Constant comparative methods were used to establish analytical distinctions (i.e. theoretical codes), facilitated by use of detailed memos, comparison tables, matrices of analytical codes and diagramming (Appendix 17 and 18). This top-down approach identified the most salient focused codes and constructed a coherent understanding of all data without the need for further revision (Appendix 19). Theoretical saturation had been reached by the eleventh interview and so no further participants were recruited.

Figure 1. Process for theoretical sampling

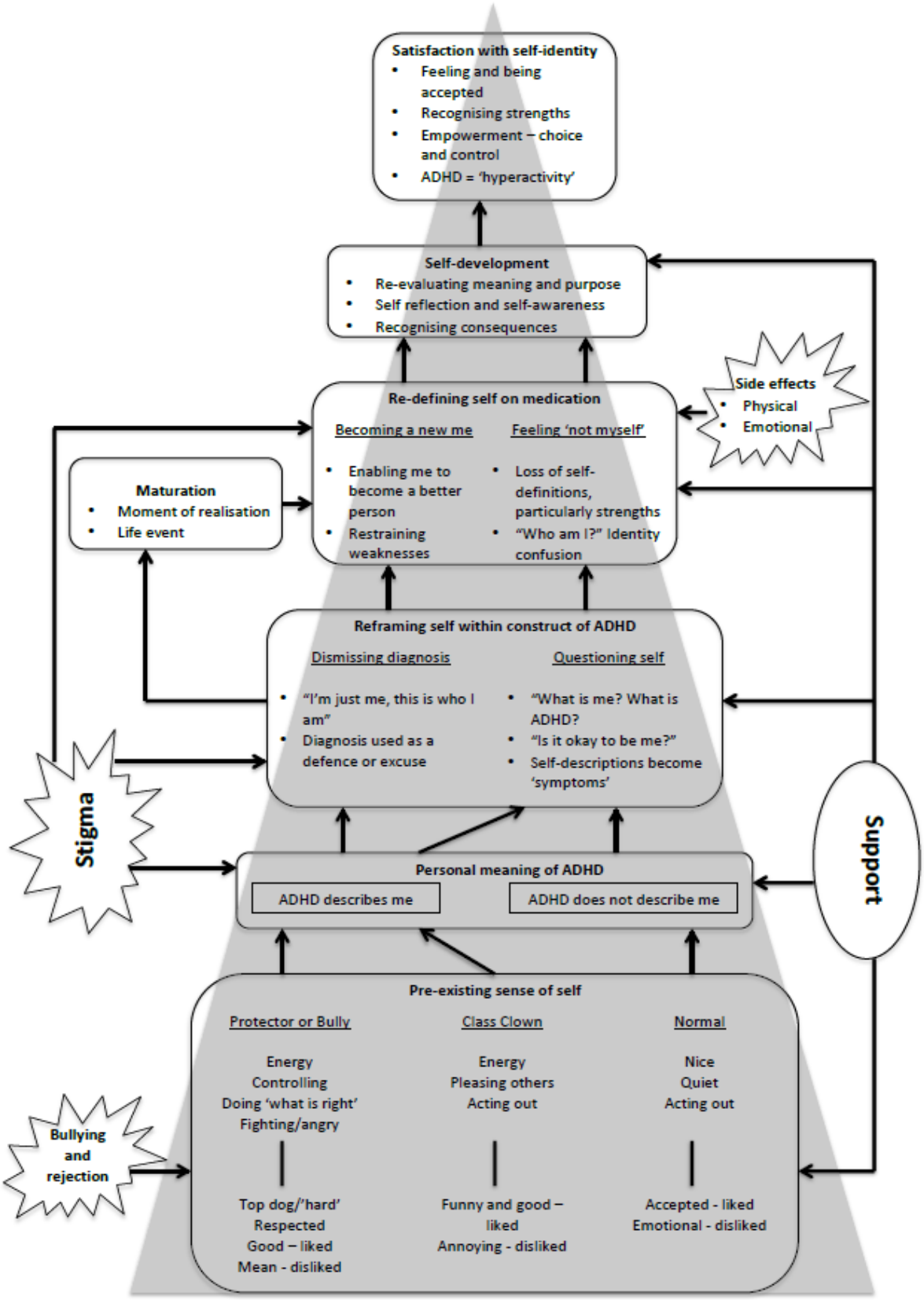


Findings

Figure 2 depicts an explanatory model of the findings, highlighting the transformation of identity over the course of middle childhood and adolescence

following a diagnosis of, and medication for, ADHD. This is visually depicted through a pyramid, with the person's pre-existing sense of self at the base of the structure and each layer shaping those above. Identity was reframed within the young person's own construction of ADHD through a process of self-reflection, and redefined following maturation and use of medication. Participants progressed up the pyramid until they achieved a sense of satisfaction with their transformed identity, where they felt empowered, accepted and valued. There was a bi-directional relationship between identity and the perceived appraisals of others throughout. At each level of the pyramid, receiving support facilitated self-development and increased the young person's understanding of self, others' appraisals of them, and consequences, leading to greater integration of identity. Stigma and rejection led to more negative self-appraisals but also developed personal resilience. Within the pyramid, three tentative trajectories were discernable between participants' narratives, determined by their pre-existing self-definitions and their perception of whether 'ADHD' was consistent with identity. The extent to which participants found the diagnosis and medication distressing was closely related to their perceived loss or alteration of self and varied widely from minimal to severe. The process of how these layers are established and interconnected is explained below, beginning with the bottom of the pyramid and moving upward in accordance with the developmental progression of participants' experiences.

Figure 2. Grounded theory model based on young people's interpretations of identity development following diagnosis of ADHD.



Pre-existing sense of self – a provisional identity

All participants described having an established sense of self prior to their diagnosis. There were three distinct themes to participants' descriptions of self. Five saw themselves as an 'aggressor' and described their role in either bullying, or protecting others or themselves (e.g. 'I used to like…bully' (Matthew); 'we were always fighting' (Lee)). Three participants saw themselves as a 'class clown', behaving to gain peer approval (e.g. '[I'd do] like just stupid stuff in lessons, always wanted to…make everyone laugh' (Sian)). A final group of three participants described their sense of self as 'just normal' prior to their diagnosis (e.g. 'I felt like a normal young girl' (Leanne)).

Fundamentally, participants' identity existed as part of a reciprocal relationship, with their perceptions of what others thought about them informing what they thought about themselves and vice versa. For example, if the young person thought others found them 'funny' and liked them, then they viewed themselves as 'funny' and appraised themselves positively. Thus, seeking the approval of their 'in-group' (e.g. peers) was crucially important for their development of identity and self-esteem.

> After fighting people … you just think, people like me because I'm doing this… you're the top dog. (Lee)

However, behaving with the aim of being liked by peers (e.g. fighting or disruptive behaviour in the classroom) often had the unintended consequence of alienating parents or teachers (i.e. the 'out-group').

> Everyone loved me…[I'd] try and make everyone laugh…Teachers hated me…Parents used to look at me in…disgust…no-one's parents really liked me. (Andrew)

Most respondents described liking themselves or feeling liked by others due to their identity, some or most of the time. For example, Tony thought he was 'good' because he was 'dead athletic', meaning his father thought he would be 'good in the army'. Andrew described how he 'liked being lively' because 'it was dead interesting' and this was fundamental to his sense of 'who I am'. Nearly all young people 'felt normal' and viewed these characteristics of self (e.g. energy, fighting, humour, aggression), as positive features of their identity. Only three of the 11 participants reported feeling that their difficulties were representative of a 'problem' or 'disorder' prior to their diagnosis. For example:

> My Mum knew that something was up and I knew something was up 'cos in school it was always she's not concentrating…my behaviour was bad. (Sian)

Bullying and rejection

Despite most participants feeling 'normal', they still identified difficulties in comparison to others. This was most notable in relation to academic work, where all but one of the participants experienced significant difficulty. Sian said, 'my memory's so bad' that 'I used to always forget stuff and just get shouted at all the time by teachers'. Before their diagnosis, all but two of the participants described feeling rejected or bullied by their peers and teachers due to their inability to meet social or academic expectations (e.g. 'they always thought they could…try and laugh at me…[because]

they knew I had a bad temper'. (Lee)). Feelings of rejection were greater where they felt there was 'something wrong' with them (e.g. 'I wouldn't act normal, I'd act strange and weird… I knew I was different' (Jamie)). This impacted on their self-esteem and identity (i.e. inadequate, failure, different).

Their subsequent behavior often represented attempts to protect their sense of self and they sought the approval and respect of others by 'standing up for what's right' and not 'backing down to anyone' (Andrew). Alternatively they distanced themselves from or rejected those that might reject them, as Mark eloquently described:

> I just thought that people didn't like me very much so…I didn't…have many mates… I stayed away from people and I got them to stay away from me. (Mark)

Personal meaning of ADHD

Most participants lacked an understanding of ADHD and many described never having heard of it before their diagnosis. Participants' construction of ADHD appeared to be determined retrospectively from their own individual difficulties and experiences. These centred on four main themes. For example, Tony described himself as 'angry all the time' but 'didn't know [he] had like a problem over it' until he was diagnosed. Thus, for Tony, ADHD was 'anger problems'. Leanne described 'a medical condition', meaning she would 'have it for the rest of my life'. Others, like Rebecca 'just thought that [it] was [a] disability'. A final group of participants described the 'normalness' of ADHD (e.g. 'I don't think ADHD is anything…its just like having hay fever' (Lee)).

Reframing self within construct of ADHD – identity confusion

Participants' pre-existing self was re-framed within the construct of ADHD and was therefore informed by the meaning of the diagnosis for themselves and others. This was coded as 'becoming the ADHD kid' and was particularly distressing for two participants, whose self-descriptions did not match their definition of ADHD. Both Rebecca and Leanne previously considered themselves 'normal' and did not feel they had any problems. To them ADHD was a 'disability' or 'medical condition', which consequently created strong feelings of distress as they attempted to consolidate it into their identity. Leanne described 'pushing people away' and 'getting upset' because she felt 'a bit funny' about the diagnosis. Similarly, Rebecca just wanted to be 'normal again instead of having it'. Rebecca described feeling different from her peers, and a sense of hopelessness after being diagnosed:

> They [peers] might feel scared…because not everyone's got ADHD…I'm a different child because I've got diagnosis but they haven't…nothing's ever going to change now.

Josh described rejecting the diagnosis as it was not characteristic of him, 'because I just feel like normal as everyone else does', therefore he did not experience any related distress.

For the remaining eight participants there was a good fit between their definition of ADHD and their pre-existing identity. For example, Mark's understanding of ADHD was that it related to 'hyperactivity', 'anger management' and 'mood swings', which 'described me to the 'T' when I was younger'. Tony described a similar experience and said, 'as soon as I got diagnosed, I knew I had it.' Some participants whose pre-existing

sense of self was a ‘protector’ or ‘bully’ described dismissing the diagnosis initially because ‘I didn’t really care’ (Matthew) so they ‘didn’t think about it’ (Lee). However some, such as Mark, used ‘ADHD’ to justify their anger: ‘when people asked me why I was angry it would just be something to say “Oh I’ve got ADHD it’s what it’s normally like… that’s the reason why.”’ However, having their ‘normal’ identity reframed as ‘ADHD’ prompted them to reflect on and question their pre-existing self. They described this making them feel like ‘I’ve got something wrong with me’, which ‘was quite scary’ (Sian) or unsettling for some participants. For example, Andrew described hiding his diagnosis from others because ‘I thought ADHD was major, like it was really something wrong with you’. This shift in identity was clearly demonstrated by Tony, who went from being ‘a normal athletic kid’ to ‘having a problem’. Thus, for the majority of respondents, this shift in identity resulted initially in a ‘loss of self’.

Stigma

‘Becoming the ADHD kid’ led others to re-frame the young person by applying their own construction of ADHD (e.g. ‘naughty’). This generally resulted in a combination of both stigma and support, and shaped the young person’s perspectives of the diagnosis and their identity. Distress arose where there were high levels of stigma and low levels of support, particularly where this led to ‘othering’ of the young person. For example, Andrew said that his teachers ‘think just because I’m an ADHD kid I expect to get away with more’, which meant ‘you could just tell they’re angry to see you’ and ‘they’d just dismiss you or they’d never pick you when you’re putting your hand up for something’, which made him feel ‘not understood’ and rejected. Rebecca described thinking ‘ADHD’ must be ‘a mongy thing because the kids were telling me that I was a mong’. Rebecca was so distressed by this stigma that she was no longer

leaving the house and said ‘that’s why I come out of school because I didn’t really want anyone to know’.

Participants described how stigma or publicising their difficulties left them feeling humiliated, hurt and angry (e.g. ‘one teacher said… “Let’s be honest Lee both of us two know that you have problems don’t we”, in front of the whole class and that just made…my blood boil’ (Lee)). They described protecting themselves from stigma or bullying through their behaviour (e.g. ‘one of them called me a weirdo but he got leathered [beaten up] so that was the end of that’ (Tony)).

In contrast, Mark described feeling supported and empowered when others recognised his strengths as a person, rather than as ‘an ADHD kid’: ‘I wasn’t seen as one of them bad kids in school…the teachers…thought kids with ADHD…was just the naughty ones in the class…so he didn’t think that I had ADHD’.

Re-defining self on medication – identity confusion

The next layer on the pyramid represented participants’ redefinition of self once they began to take medication.

Side effects: Participants described significant physical and emotional side effects such as headaches, heart palpitations, feeling sick, changes in mood, tiredness, lethargy, loss of appetite, lacking interest in activities or socialising, and feeling depressed (e.g. ‘I felt like a zombie and I didn’t feel healthy’ (Andrew)). This further impacted upon their sense of self, as it was ‘alien’ compared to how they were before the medication. Derek described how he was ‘moody all the time’ from lack of food and sleep, which made him feel like he ‘didn’t want to talk to anyone’. Eight of the participants described significantly disliking the medication and its effects, and thought it had made them feel worse.

> You were up there high…and when I'm on my medication I just feel like…low… don't speak, just don't even get up…it just makes you that tired…I prefer myself to be like this now [off medication] like where I can talk and where I can do stuff instead of feeling like that. (Sian)

All of the participants apart from Josh reported an altered sense of self after taking medication. Some described this as a 'loss' while others described this as 'becoming a better person'. Others felt the medication was a tool to manage their behaviour but only for short periods, when needed.

Feeling 'not myself: Most participants felt that medication removed the positive characteristics comprising their core self, without replacing these with alternatives. For example Tony described how he 'was proper athletic', able to 'run', 'do sports' and felt he could 'do everything, do absolutely anything' because he 'just wouldn't run out of energy'. When he took medication he no longer had these perceived strengths, which meant 'I'd feel weird, like I won't feel like me' and said 'that's what I don't like about taking them…I felt like different…they were changing me and I didn't want to change'. He also said this meant, 'it just all went boring' because instead of doing activities he felt good at and enjoyed, he was 'staying in class and doing like my lessons', something he did not feel was enjoyable or one of his strengths. Derek similarly went from being 'dead active' to 'chilled out' when he took medication and said he 'just didn't like the feeling of it. I just didn't like it.' Participants like Sian recognised that medication is 'trying to make you concentrate' but did not feel that accounted for how it 'really affected me, like where you just don't feel yourself. You should feel yourself'.

Becoming a new me: Following a process of maturation (described below) some participants described a shift in their values and perspectives to those that were more culturally accepted and gained new purpose and meaning. Consequently, they began to appreciate the influence of medication on their identity. They recognised medication suppressed those aspects of themselves that made them 'different', which enabled them to be accepted by others and society. For example, Matthew described 'knowing that I need to take tablets for me to be a different person, well like have a different personality from what I used to have'. Whilst needing tablets annoyed him, he also said 'I enjoy having them because I don't want people thinking, you know the bad of me. So its 50/50.' Similarly, other participants like Derek said they 'understand that I have to take my tablet now' to help them 'concentrate on my work' in certain contexts like school, college or work 'for my future', since 'getting a good job' was more important to them now 'because I'm older'. Notably, only participants who felt medication suppressed their 'difficulties' whilst not eradicating their strengths or characteristics comprising their core identity shared this view. Maintaining a sense of their strengths and 'liked' aspects of self was essential for participants' development of a positive sense of self whilst using medication.

Maturation – identity consolidation

Seven participants described a 'turning point' that led them to form a new understanding of their diagnosis and identity. For some participants, this turning point appeared to arise from realising the harmful consequences of their behaviour. For example, Mark said he 'realised I shouldn't be [fighting] because there was always going to be someone that will be stronger' and who could 'beat' him so he thought he 'should stop before that happened'. Similarly Lee said that ' one day there's just gonna be someone bigger than me…going to hurt me…so I just stopped being naughty and

fighting'. Some participants came to this conclusion by learning from others. For example:

> [I know someone] who is just like me but he's older…he said he ruined his life through messing about in school getting kicked out…[now] he's got no money and he has to like scrape money out just to buy food and obviously I don't want to be like that. (Derek)

For other participants this 'realisation' appeared to be related to a significant life event. Matthew shared that his 'Dad passed away when I was 15' and said 'that's probably why…I just like clicked in my head and thought I need change you know... Because life is too short isn't it'. Others described how leaving school and moving to college or away from their friends produced these reflections of change. For these individuals, such an event led to a shift in their values and perspectives about themselves and the world around them and resulted in their active choice to adopt a different approach in their behaviour or relationships, prompting self-development.

Support

The provision of support varied widely between recruitment sites. One area provided substantial support through a large ADHD charity and the other area only reviewed medication. Some participants, like Tony, described being supported academically by teaching assistants (TA), which 'was good' because they 'proper helped', and acknowledged participants' strengths or improvements (e.g. 'the teacher said to me that you are coming on a lot' (Rebecca)). Rebecca also described how 'a lot of the kids helped' her because they 'understood'. Academic support provided a buffer

against feelings of failure and inadequacy, fostering more positive self-esteem and identity.

Sian, Rebecca and Josh described receiving additional one-to-one emotional support in a separate classroom, and Mark and Sian received psychological support, mainly provided by one large ADHD charity. This included 'groups where you sit round and [they] ask how you feel' (Sian), and one-to-one counselling:

> [The counsellor] helped me a lot…with homework and…gave me advice on some tactics to do to stop me getting as angry or…talked to me and keep me calm and asked me how my day was, and that which was just probably something I needed…someone there to talk to and knowing that it wouldn't go anywhere else'. (Mark)

Sian 'love[d] going' and felt this support had been 'helpful because it's showing you how to reflect on what you've done instead of just getting put in a room, getting told not to move or you can't go to the toilet or whatever', which highlighted her desire to be acknowledged, empowered and autonomous. Those who had received more emotional support demonstrated a far greater understanding of self, others' appraisals of them, and consequences, and felt more satisfied with their identity and decision-making capability. Interestingly, individuals who described utilizing support did not describe experiencing a 'turning point' as outlined earlier but engaged in self-development over time. Some participants, like Leanne, believed they 'could have done with the support younger rather than getting it half way through my life', which may have meant they 'wouldn't have been as bad' (Sian).

Other participants described rejecting offers of support where these were pushed upon them, rather than being approached collaboratively. For example, Andrew explained that he 'refuse[d] to go to therapy' because he felt able to 'deal with it on my own'. These participants appeared to see support as confirmation that they were unable to cope, or 'different from normal' (Lee), compounding their feelings of inadequacy.

Self-development – identity consolidation

Young people described 'growing up' as a process of learning about the self, others, and the consequences of their actions through self-reflection. Participants talked about how increasing self-awareness helped them to develop self-control over their emotions and behaviour:

> As I've got older I've matured more so…I've started thinking more about what I do before I lash out at someone and hit them…I realised…what I was doing was wrong and that…I should stop' (Mark)

Similarly Tony said: 'Like I actually know what I'm thinking now, back then I didn't, I was just a little b*****d'. Sian called this 'developing conscience': 'I feel like I've got more control over my behaviour…con-science or something…I've got more of that… I'm a bit more aware.' Self-control was also related to participants' ability to see the potential consequences of their behaviour (e.g. 'I just can't be bothered with all the hassle afterwards (Mark))

Some participants described developing new meaning and purpose, which altered the aim and direction of their actions into something deemed more culturally appropriate. Matthew discussed it being 'important' for him to pass his re-sit GCSEs

and ‘that’s why I’m getting my…head down and doing my work.’ Mark started volunteering at weekends and said this had taught him ‘to keep me cool’.

Satisfaction with self-identity

At each stage of the pyramid, participants reflected on how their new experiences and understandings resonated with their pre-existing self and attempted to integrate these together, leading them to redefine, reframe and transform their identity. This took them first through a process of identity confusion and consolidation before reaching the pinnacle of the pyramid where they described generally feeling satisfied with their identity. The eight participants who reached this stage felt they were accepted as a whole person, with recognised strengths as well as difficulties. This was coded as ‘shifting from a problem to a person with a problem’, illustrated by the following quote from Andrew:

> Okay maybe I’m not perfect, maybe I’m not…a grade A student…but…I’m unique…and I think…that should be enough, to just say like I don’t have to be like everyone else…I think I’m quite alright as far as people go.

Participants’ understanding of ADHD shifted from being ‘who I am’ to being ‘just a bit hyperactive’, meaning that participants like Lee learned not to see ADHD as being ‘different to anything else’. He said later, ‘none of my mates have ADHD and I’m probably one of the most normal out of all of them… I’m not different in any way’.

Participants described feeling as though others accepted and empowered them to be autonomous decision-makers, which contrasted with their earlier feelings of disempowerment. Four participants decided to stop medication, two used medication selectively (e.g. ‘for schoolwork’ (Derek)), and three made the decision to continue

taking medication. Being empowered led participants to feel 'like I've got more…independence in myself' (Sian), whilst feeling supported (e.g. 'the teachers [in college] are so much different...they sit there and they listen and they help you').

Discussion

This study explored older adolescents' retrospective experiences of identity development after being diagnosed with ADHD when aged 8-13. This extended existing research, by allowing for reflection on key identity transitions and the impact of various factors over time. Participants' stories mostly highlighted a difficult process of identity transformation. They described struggling to integrate their diagnosis or their 'new personality' on medication into their identity, resulting in feelings of loss and/or confusion. Formal or informal support and maturational processes facilitated self-development and identity consolidation. Developing self-awareness, autonomy and recognizing strengths led to an understanding of self as a 'whole' person, not defined by a 'disorder'. These detailed, longitudinal narratives from adolescents reinforce the need for individualized holistic formulations, which contextualize participants' strengths and difficulties, and account for complexity. The findings also emphasize the importance of providing a reflective space for young people's development of self-awareness, self-esteem and identity consolidation.

In the current study, participants described having established a provisional identity encompassing both their strengths and difficulties, before being diagnosed with ADHD. Being the 'class clown' or a 'protector' led participants to feel accepted and liked by their peer group, meaning these characteristics (e.g. energetic, angry, 'tough' or funny) were valued and crucial for their positive sense of self. This differed from previous studies, which emphasized negative self-appraisals (e.g. Hallberg et al., 2010; Krueger & Kendall, 2001; Sikirica et al., 2015). Consistent with findings from previous

research, participants experienced challenges where their attributes restrained them from meeting valued societal norms and expectations (e.g. high academic achievement, fighting) (Brinkman et al., 2012; Gallichan & Curle, 2008; Hallberg et al., 2010; Levanon-Erez, Cohen, Traub Bar-Ilan, & Maeir, 2017). As explained by Erikson's (1993) developmental model, societal approval determined participants' sense of competence or inadequacy, with peer group approval being particularly salient for their self-esteem. This explains participants' preference in the current study for 'in-group' (peers) positive appraisals, at the expense of their 'out-group' (e.g. parents and teachers).

Similar to young people in previous qualitative research (Avisar & Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014; Knipp, 2006; Sikirica et al., 2015; Wiener & Daniels, 2016), the participants in this study held varying understandings of ADHD and few considered it the 'medical' disorder relating to hyperactivity, impulsivity and inattention outlined by the DSM-5 (American Psychiatric Association, 2013). Instead, participants appeared to construct their understanding of ADHD retrospectively to account for their own unique difficulties (e.g. academic disadvantage, emotion regulation problem, aspect of personality). Most participants felt their difficulties were 'normal', and did not feel there was a specific deficit in their functioning. Thus, being diagnosed with a 'disorder' (ADHD) 'medicalized' or 'pathologized' young people's experiences, as they became 'an ADHD kid' with 'symptoms'. This resulted in identity confusion and participants began to question their idea of 'self' as it existed within the construct of ADHD (i.e. 'what is ADHD and what is me?'). Modified labeling theory (e.g. Link, 1987) suggests that being 'the ADHD kid' may have activated societal ideas and expectations, both for others and the participants themselves, such as having 'too much energy', 'being angry' and 'naughty' (rather than

being energetic, enthusiastic and well-liked). Consequently, previously considered strengths may have become attributed to the presence of a 'disorder' and 'badness' or 'wrongness', leading some participants to question 'is it okay to be me?' This may have impacted negatively upon their sense of competence and self-esteem and amplified feelings of inferiority (Erikson, 1993).

The social model of disability provides an alternative understanding of difficulties to the medical model. Specifically, it argues that young people are 'disabled' by their context (e.g. school), if it does not adapt to account for their individual differences. Gallichan and Curle (2008) called this 'square pegs fitting into round holes', with the mismatch between the young person and their environment being responsible for lower self-esteem and a more negative sense of self. The current study found that ADHD became a 'vicious cycle' or self-fulfilling prophecy for some participants, whereby their identity as 'an ADHD kid' fostered expectations of future failure, inadequacy, rejection, and hopelessness regarding the possibility for change, which produced further difficulties, and an internalization of their identity as a 'failure'. Stigma exacerbated this cycle, as others' expectations of the young person (e.g. 'naughty' or disruptive) led them to become hyper-vigilant to any transgressions. Thus the young person experienced frequent reproof, which damaged relationships and increased their feelings of lost control, anger and frustration, and in turn exacerbated their behaviour. This effect was reversed where the young person's environment adapted to their needs, emphasizing the role of societal responses in the development of identity and self-esteem.

Consistent with other qualitative research, participants in this study largely described feeling their thoughts and feelings were invalidated and not understood by others, particularly in relation to medication and other intervention strategies (Avisar &

Lavie-Ajayi, 2014; Brinkman et al., 2012; Charach et al., 2014; Knipp, 2006; Singh, 2012). The current study found that most adolescents did not view their characteristics as a 'disorder' requiring a 'cure'. Rather they described needing to develop their 'self-control' to enable them to meet the varying expectations of their different contexts. Some participants felt they gained this through medication; others emphasized the role of support in developing their self-awareness, reflective function and consideration of consequences.

Since the aim of medication is to alter personal attributes (i.e. hyperactivity, impulsivity and inattention), it is understandable that this resulted in participants experiencing a loss of self (Avisar & Lavie-Ajayi, 2014). Notably, in the current study, participants described this being due to medication suppressing the aspects of self they considered strengths comprising their core being (e.g. energy, being good at sport, sociable, funny, 'hard' etc.). Without these characteristics, participants described no longer 'feeling themselves' and instead feeling like a 'zombie' or 'depressed', which resulted in altered peer appraisals. Interestingly, some participants described beginning to value medication during later adolescence, but significantly, only after they had matured and shifted their values and purpose towards more socially accepted goals (e.g. college, work, GCSEs). This fits with Erikson's (1993) stage of identity development between the ages of 12 and 18, when young people negotiate their role and identity following a period of confusion to determine 'who I want to be'. Erikson argues that pressurizing someone into an identity may result in their rebellion and a negative sense of self, thus they need to have chosen the redirection of identity themselves. This is consistent with the 'stages of change model', which emphasizes the importance of a person's desire and readiness to change (Prochaska & DiClemente, 1986). However, medication required participants to 'become a new me' by incorporating their altered

personality on medication into their identity, when they may not yet have been ready. In the current research, some participants attempted to retain their authentic identity by using medication selectively, which resulted in their adoption of a 'second personality', similar to the young people in Singh's (2012) study. These findings highlighted the complexity young people's treatment decisions, which encompassed the influence of identity.

Crucially, this study found that participants who received more emotional support demonstrated a far greater understanding of self, others' appraisals of them, and consequences. Some of those who did not receive this support developed these capabilities following a process of maturation, which facilitated self-reflection. This extended existing research on the topic, which had not previously explored young people's development over time. In this study, participants' self-development enabled them to think critically about their experiences, which prompted a shift in their perspectives and sense of purpose. Similar to findings from existing research, participants who felt respected, validated, and empowered to be autonomous decision-makers demonstrated more competence in their abilities and had higher self-esteem (e.g. Brinkman et al., 2012; Charach et al., 2014; Gallichan & Curle, 2008). This enabled the young person to develop self-regulation through various means (e.g. medication, support, re-direction toward purposeful activity) in order to have more control, choice and autonomy over their self-management. The recognition that participants had strengths as well as difficulties enabled them to feel accepted as a whole person, wherein ADHD existed as just an aspect of their identity (e.g. 'just a bit hyperactive'), rather than being defining feature. It was this independence, feeling of competence and sense of self as a 'whole' person with appreciated strengths that facilitated participants' satisfaction with self, even where stigma was experienced.

Implications for clinical practice

As demonstrated by the findings of this study, it is crucially important that services consider whether diagnosis and medication is helpful for children and young people referred for difficulties with hyperactivity, impulsivity and inattention, before proceeding with the diagnostic process. Most young people in this study did not feel they had a 'problem' and often considered the 'symptoms' of ADHD personal strengths. In these cases, the diagnosis itself invalidated their narrative of 'strength' by imposing a narrative of 'illness', and implied a necessity for change. This exacerbated some young people's distress, as it compounded their feelings of difference, inferiority and confusion regarding 'who I am'. Therefore, for some young people, diagnosis may amplify their sense of 'impairment' and have a negative impact on their functioning. Instead, developing a holistic contextual understanding of a young person's difficulties and strengths through the use of formulation may be more appropriate (British Psychological Society, 2013, 2015). Wherever possible this ought to be done collaboratively with the young person, to encompass and validate their views, and develop their self-awareness.

Whether a diagnosis is given or not, this research highlights the importance and clinical utility of facilitating an open-dialogue where young people can reflect upon and attribute meaning to their previous experiences. The current study suggests that intervention needs to be strengths-based, and emphasize resilience, resource, and positive aspects of self. Where a diagnosis of ADHD is provided, facilitated discussion ought to deconstruct the meaning of ADHD, and externalize this concept to establish the young person as a distinct 'self', influenced but not defined by ADHD. Another implication of the current study is that participants who had received one to one support

had greater self-esteem, self-awareness and reflective function, indicating that this is an effective intervention for promoting positive and integrated identity.

Participants in the current study suggested that they had limited power in their care and treatment, with others making decisions for them (e.g. regarding medication). Thus it is important that young people are enabled to provide consent where appropriate, and be involved in decisions regarding their care. Where relevant, Gillick competence should be assessed, to ensure informed consent to assessment and treatment. Remaining mindful of the power differential and clinical importance of gaining young people's perspectives can empower practitioners to remain curious, collaborative and recognize young people's 'expertise' in what is most helpful for them (Allan & Harwood, 2013). In turn, this will validate young people's experiences, empowering them to adopt a more active role in decision-making and self-regulation, promoting feelings of acceptance, higher self-esteem and identity consolidation.

Whilst the theoretical model represents an interpretation of participants' narratives, it is equally as important to acknowledge that this remains grounded in the facts of their experiences. Participants within this study often highlighted difficult experiences and adversity, including bullying, parental divorce and exposure to crime or violence, and thus appeared relatively open about their experiences. This suggests that any influence arising from the potential bias of social desirability did not significantly impact upon participants' narratives. Clinically, it is important to remember that children and young people may have experienced similar adversity. Whilst this is not necessarily captured within the model, it is important it is not overlooked, and is included in the formulation of the young person's problems.

Finally, young people in this study consistently highlighted the significant negative impact of medication and its side effects. It is important that clinicians

adequately account for young peoples views and experiences, and remain aware of the power imbalance and difficulty young people may have voicing any concerns.

Strengths and limitations

This study addressed a gap in the literature, by analyzing older adolescents' retrospective accounts of how their ADHD diagnosis impacted on their identity over time. Participants' narratives were both rich and reflective due to the flexible and curious nature of the interview. Using a social constructionist grounded theory framework enabled us to explore identity transformation throughout childhood and adolescence and identify the various stages and trajectories involved, culminating in the proposal of a detailed explanatory model. To ensure the research was high quality, guidelines for undertaking and documenting qualitative research were followed throughout all stages of the study (Walsh & Downe, 2006).

However, despite recruiting from a wide population, only clinical populations were recruited into the final sample, highlighting one potential limitation and a possible avenue for future research. A further limitation is that all participants took medication upon first being diagnosed with ADHD. This may have impacted on their construction of ADHD as something that required medication to be 'fixed', despite this being a typical experience of diagnosis/treatment. Nevertheless, grounded theory does not seek to generalize the findings to all children diagnosed with ADHD. Instead the approach aims to identify key theoretical categories and the relationships between them rather to provide a helpful framework for clinicians considering the needs of children and young people (being) diagnosed with or receiving intervention for ADHD.

Suggestions for future research

Further research could explore how being diagnosed at a younger age (e.g. age 5-7 years), where children may have a different or less complex understanding of self or the diagnosis of ADHD, would affect their identity formation.

Future research could focus upon exploring the differences in identity formation for those who have received a medical diagnosis of ADHD compared to those who have received a psychosocial explanation of their difficulties (e.g. through formulation). The findings of this research would have significant implications for considering the usefulness of diagnosis and formulation in supporting young people with difficulties surrounding hyperactivity, impulsivity and inattention.

For all participants in this study, diagnosis and medication occurred simultaneously, suggesting that medication is synonymous with ADHD and considered a first-line treatment. Exploring the differences in identity formation between those who were diagnosed with ADHD and took medication compared to those who were diagnosed but chose alternative interventions would provide insights into the usefulness of medication for young people with these difficulties.

Conclusion

Adolescents found that integrating a diagnosis of ADHD or a 'new personality' on medication into their identity was challenging and resulted in feelings of loss and/or confusion. This study emphasized the need for a validating, strengths-focused approach to both assessment and intervention for individuals experiencing difficulties with hyperactivity, impulsivity and inattention, which would facilitate self-reflection and the development of self-awareness, self-esteem and understanding of consequences. Individualized holistic formulations can contextualize young people's strengths and

difficulties, enabling them to consolidate their identity rather than feeling defined by their ‘disorder’.

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Appendix 1

Author guidelines for Emotional and Behavioural Difficulties

About the journal: *Emotional and Behavioural Difficulties* is an international, peer-reviewed journal, publishing high-quality, original research. The journal's central intention is to contribute to readers' understanding of social, emotional and behavioural difficulties, and also their knowledge of appropriate ways of preventing and responding to EBDs, in terms of intervention and policy.

The journal aims to cater for a wide audience, in response to the diverse nature of the professionals who work with and for children with EBDs.

Please note that this journal only publishes manuscripts in English.

Preparing your paper

Structure: Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Word limits: Please include a word count for your paper. A typical article for this journal should be no more than 8000 words; this limit includes tables, references, figure captions, footnotes, endnotes.

Formatting and templates: Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. Word templates are available for this journal. Please save the template to your hard drive, ready for use.

References: The author-date system is widely used in the physical, natural and social sciences. For full information on this style, see The Chicago Manual of Style (16th edn) or http://www.chicagomanualofstyle.org/tools_citationguide.html

Checklist: what to include

Author details. Please include all authors' full names, affiliations, postal addresses, telephone numbers and email addresses on the title page. Where available, please also include ORCID identifiers and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted.

A non-structured **abstract** of no more than 150 words.

Four to five **keywords**

Funding details. Please supply all details required by your funding and grant-awarding bodies.

Disclosure statement. This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research.

Geolocation information. Submitting a geolocation information section, as a separate paragraph before your acknowledgements, means we can index your paper's study area

accurately in JournalMap's geographic literature database and make your article more discoverable to others.

Supplemental online material. Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare.

Figures. Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for color, at the correct size). Figures should be saved as TIFF, PostScript or EPS files.

Tables. Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

Equations. If you are submitting your manuscript as a Word document, please ensure that equations are editable.

Units. Please use SI units (non-italicized).

Using third-party material in your paper: You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission.

Style guidelines

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy. Please use British -ise spelling style consistently throughout your manuscript. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Font: Times New Roman, 12 point, double-line spaced. Use margins of at least 2.5 cm (or 1 inch).

Title: Use bold for your article title, with an initial capital letter for any proper nouns.

Abstract: Indicate the abstract paragraph with a heading or by reducing the font size. Check whether the journal requires a structured abstract or graphical abstract by reading the Instructions for Authors. The Instructions for Authors may also give word limits for your abstract. Advice on writing abstracts is available **here**.

Keywords: Please provide keywords to help readers find your article. If the Instructions for Authors do not give a number of keywords to provide, please give five or six.

Headings: Please indicate the level of the section headings in your article:

- First-level headings (e.g. Introduction, Conclusion) should be in bold, with an initial capital letter for any proper nouns.
- Second-level headings should be in bold italics, with an initial capital letter for any proper nouns.
- Third-level headings should be in italics, with an initial capital letter for any proper nouns.

- Fourth-level headings should be in bold italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.
- Fifth-level headings should be in italics, at the beginning of a paragraph. The text follows immediately after a full stop (full point) or other punctuation mark.

Tables and figures: Indicate in the text where the tables and figures should appear, for example by inserting [Table 1 near here]. The actual tables should be supplied either at the end of the text or in a separate file. The actual figures should be supplied as separate files. The journal Editor's preference will be detailed in the Instructions for Authors or in the guidance on the submission system. Ensure you have permission to use any tables or figures you are reproducing from another source.

Running heads and **received dates** are not required when submitting a manuscript for review; they will be added during the production process.

Spelling and punctuation: Each journal will have a preference for spelling and punctuation, which is detailed in the Instructions for Authors. Please ensure whichever spelling and punctuation style you use is applied consistently.

Queries

Should you have any queries, please visit our Author Services website or contact us at authorqueries@tandf.co.uk.

Updated February 2017

Appendix 2

Example search strategy

1. "Young person"
2. Child*
3. Adolescent
4. "Young adult"
5. "Young man"
6. "Young woman"
7. Girl
8. Boy
9. Youth
10. Experiences
11. Expectations
12. Opinions
13. Stories
14. Narratives
15. "Life experiences"
16. ADHD
17. "Attention deficit hyperactivity disorder"
18. "Attention deficit disorder with hyperactivity"
19. "Attention deficit disorder"
20. Qualitative
21. "Grounded theory"
22. "Interpretative phenomenological analysis"
23. IPA
24. "Thematic analysis"
25. "Content analysis"
26. "Narrative analysis"
27. Interview*
28. "Focus groups"
29. 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33
30. 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9
31. 10 OR 11 OR 12 OR 13 OR 14 OR 15
32. 21 OR 22 OR 23 OR 24
33. 30 AND 31
34. (30 AND 31) AND (32 AND 33)
35. 29 AND 34

Appendix 3

Inclusion and exclusion criteria

Study Parameters	Inclusion Criteria	Exclusion Criteria
Sample/population	Adolescents (aged 13-18) who have been formally diagnosed with ADHD Both genders All cultural backgrounds	Interviews with children younger than 13 Interviews with adults older than 18
Study focus	Studies that directly explore the narratives and views of adolescents with ADHD Studies that explore YP's experiences within any aspect of life related to their diagnosis (e.g. school, home, medication, services)	Studies that focus on others' perspectives (e.g. views of parents, teachers, professionals), including where these cannot be distinguished from the views of YP in the analysis (i.e. dyad studies) Studies that focus exclusively on YPs experiences of treatment or interventions (e.g. CBT, support groups, medication), unless the study also explores narratives surrounding their diagnosis
Methodology	Studies that employ qualitative methods of data collection and analyses e.g. interviews, focus groups, open-ended surveys May include mixed methods of quantitative and qualitative	Studies that exclusively use quantitative methods of data collection and analysis, including studies that summarise qualitative data quantitatively
Language	English or translated into English only	Not written or translated into English
Study type	Peer reviewed primary research	Book reviews, book chapters, opinion pieces, commentaries, literature reviews, dissertations or unpublished theses, non-peer reviewed journal articles

Appendix 4

Quality assessment tool (Walsh & Downe, 2006)

Table 4 Summary criteria for appraising qualitative research studies.

Stages	Essential criteria	Specific prompts
Scope and purpose	Clear statement of, and rationale for, research question/aims/purposes	• Clarity of focus demonstrated • Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing • Link between research and existing knowledge demonstrated
	Study thoroughly contextualised by existing literature	• Evidence of systematic approach to literature review, location of literature to contextualise the findings, or both
Design	Method/design apparent, and consistent with research intent	• Rationale given for use of qualitative design • Discussion of epistemological/ontological grounding • Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology) • Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims • Setting appropriate
	Data collection strategy apparent and appropriate	• Were data collection methods appropriate for type of data required and for specific qualitative method? • Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail? • Was triangulation of data sources used if appropriate?
Sampling strategy	Sample and sampling method appropriate	• Selection criteria detailed, and description of how sampling was undertaken • Justification for sampling strategy given • Thickness of description likely to be achieved from sampling • Any disparity between planned and actual sample explained
Analysis	Analytic approach appropriate	• Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory) • Was it appropriate for the qualitative method chosen? • Was data managed by software package or by hand and why? • Discussion of how coding systems/conceptual frameworks evolved • How was context of data retained during analysis • Evidence that the subjective meanings of participants were portrayed • Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance • Did research participants have any involvement in analysis (e.g. member checking) • Evidence provided that data reached saturation or discussion/rationale if it did not • Evidence that deviant data was sought, or discussion/rationale if it was not
Interpretation	Context described and taken account of in interpretation	• Description of social/physical and interpersonal contexts of data collection • Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena
	Clear audit trail given	• Sufficient discussion of research processes such that others can follow 'decision trail'

Table 4 (*continued*)

Stages	Essential criteria	Specific prompts
	Data used to support interpretation	• Extensive use of field notes entries/verbatim interview quotes in discussion of findings • Clear exposition of how interpretation led to conclusions
Reflexivity	Researcher reflexivity demonstrated	• Discussion of relationship between researcher and participants during fieldwork • Demonstration of researcher's influence on stages of research process • Evidence of self-awareness/insight • Documentation of effects of the research on researcher • Evidence of how problems/complications met were dealt with
Ethical dimensions	Demonstration of sensitivity to ethical concerns	• Ethical committee approval granted • Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants • Evidence of fair dealing with all research participants • Recording of dilemmas met and how resolved in relation to ethical issues • Documentation of how autonomy, consent, confidentiality, anonymity were managed
Relevance and transferability	Relevance and transferability evident	• Sufficient evidence for typicality specificity to be assessed • Analysis interwoven with existing theories and other relevant explanatory literature drawn from similar settings and studies • Discussion of how explanatory propositions/emergent theory may fit other contexts • Limitations/weaknesses of study clearly outlined • Clearly resonates with other knowledge and experience • Results/conclusions obviously supported by evidence • Interpretation plausible and 'makes sense' • Provides new insights and increases understanding • Significance for current policy and practice outlined • Assessment of value/empowerment for participants • Outlines further directions for investigation • Comment on whether aims/purposes of research were achieved

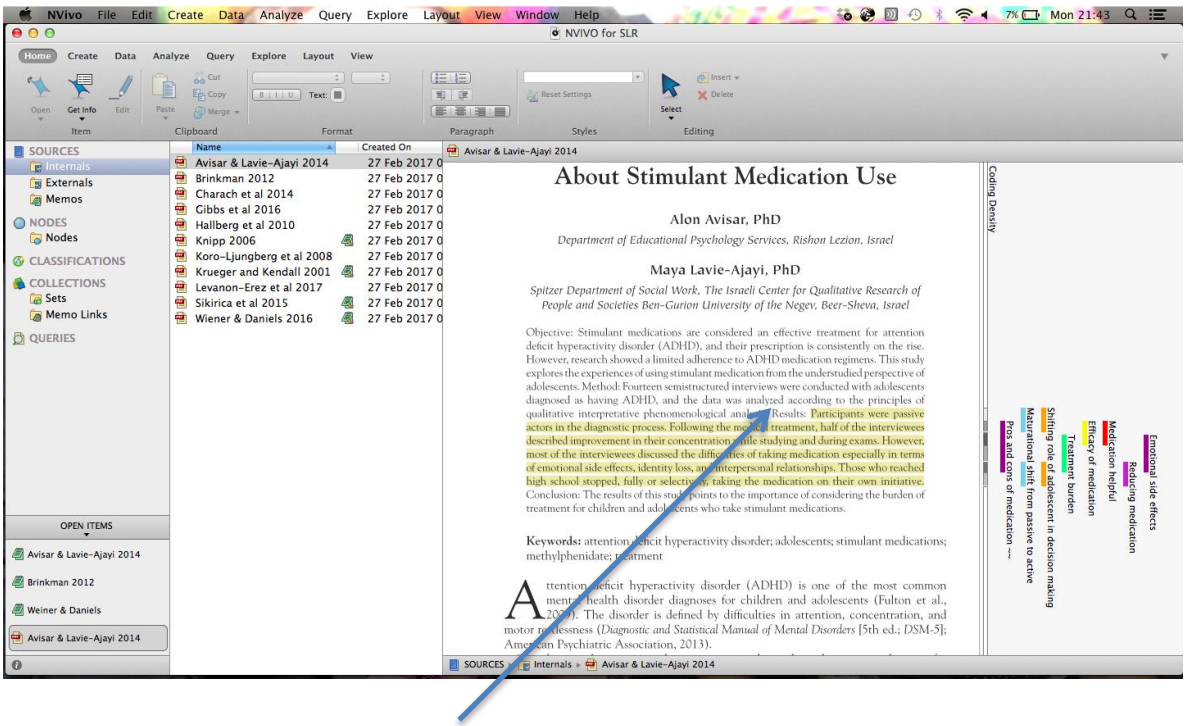
Appendix 5

Quality appraisal table

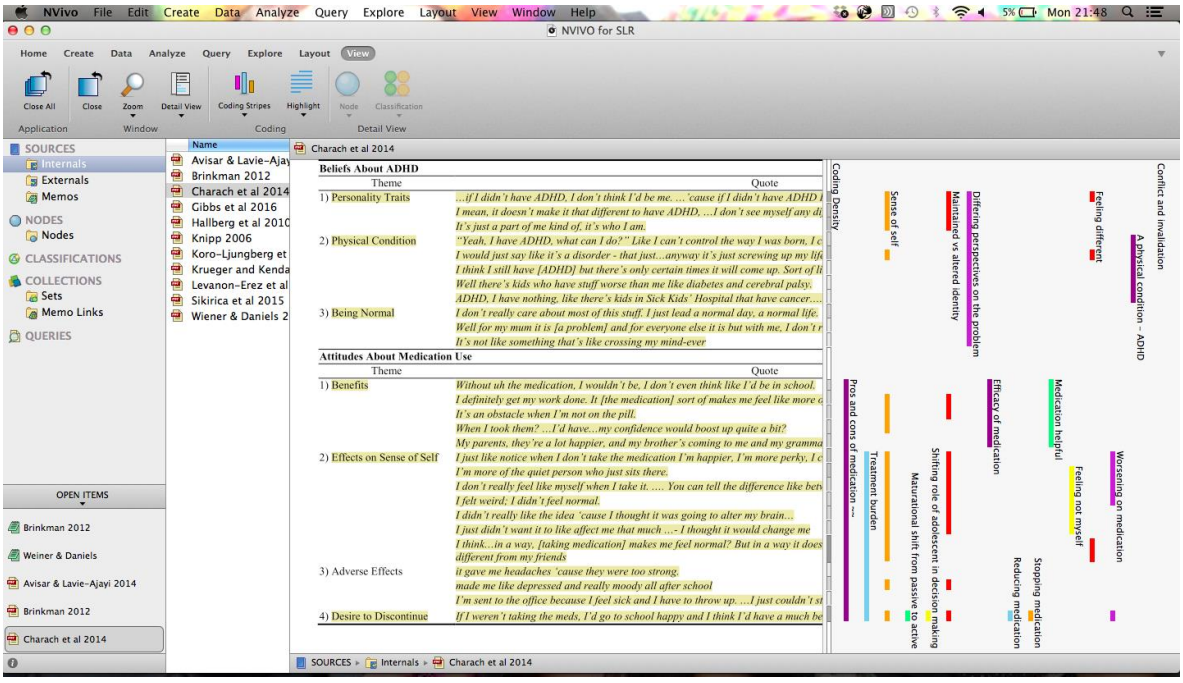
	Paper	Avisar 2014	Brinkman 2012	Charach 2014	Gibbs 2016	Hallberg 2010	Knipp 2006	Koro-Ljungberg 2008	Krueger 2010	Levanon-Erez 2017	Sikirica 2015	Weiner 2016
Stage	**Essential criteria breakdown**											
Scope and purpose	*Clear statement of, and rationale for, research question/aims/purposes*	1	1	1	1	1	1	1	1	1	1	1
	Study thoroughly contextualised by existing literature	1	0.5	1	1	1	1	1	1	1	1	1
Design	*Method/design apparent, and consistent with research intent*	1	0	0	1	1	0	0	1	1	1	0.5
	Data collection strategy apparent and appropriate	1	1	1	1	0.5	1	1	1	0	1	1
Sampling strategy	*Sample and sampling method appropriate*	1	1	1	1	1	1	1	1	1	1	1
Analysis	*Analytic approach appropriate*	1	1	0.5	1	1	0	1	1	1	1	1
Interpretation	*Context described and taken account of in interpretation*	1	1	1	1	1	0	1	1	0	1	1
	Clear audit trail given	0	1	1	1	0.5	1	1	1	1	1	1
	Data used to support interpretation	1	1	1	1	1	0.5	1	1	1	1	1
Reflexivity	*Researcher reflexivity demonstrated*	0	0	0	1	0	0	1	1	0	0	0
Ethical dimensions	*Demonstration of sensitivity to ethical concerns*	1	1	1	0	1	1	1	0	1	1	0
Relevance and transferability	*Relevance and transferability evident*	1	1	1	1	1	1	1	1	1	1	1
	TOTAL/12	**10**	**9.5**	**9.5**	**11**	**10**	**7.5**	**11**	**11**	**9**	**11**	**9**

Appendix 6

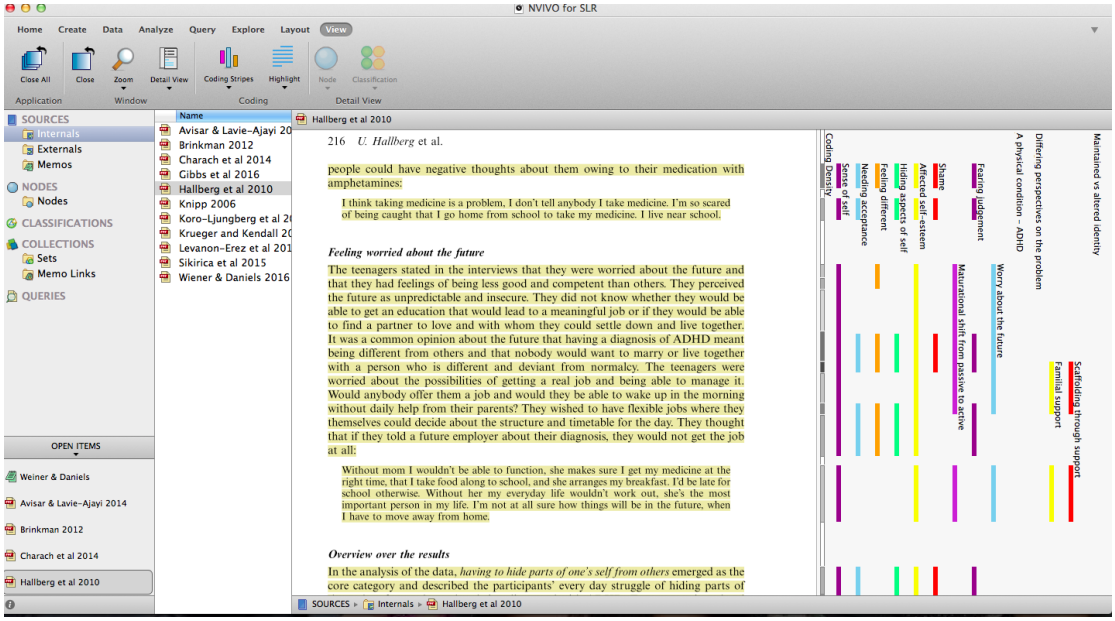
Coding examples for thematic synthesis



All text labelled ‘results’ or ‘findings’ was coded line by line as raw data.



This included any direct quotes from participants, or author codes, including data displayed in tables



It also included everything written in the findings section

Following the coding of each paper, memos were written in NVIVO, for example

This read as a well-written and detailed results section, wherein I felt I learnt a great deal regarding each participant's experience and the general themes that were coming up.
I felt like each theme was grounded fully in the data and detailed quotes contextualised each theme.
Each theme seemed equally important and was fully explored; the paper really denoted the YPs experiences.
The focus on medication had lead to other discoveries surrounding identity, the burden of treatment and the invalidation young people experiences as a result of lacking choice and autonomy in making independent or collaborative treatment decisions. This was interesting because it emphasised the extent of this distress upon the young person as being equal to the distress of the side effects. Young people had not been given a voice over what happened to them. Instead their parents made these decisions and did not listen to, understand, acknowledge or validate their concerns.
I was surprised at the extent of the treatment burden highlighted by the paper. The distress caused was very significant compared to the minor benefits detailed. The benefits of medication seemed constrained to 'fitting the box of academia'. In all other regards medication was not helpful, or unhelpful. It therefore seemed a very important recommendation of the paper that YP were encouraged to reject medication or make their own decisions about what is right for them.
The paper also emphasised YPs unique experiences, weighing up the pros and cons of meds and these will be different for each of them. The paper was advocating for YP to play an active role in this decision making process, which felt really important.
The paper also recognised that these decisions seemed likely to be increasingly taken by YP over time regardless and that as YP got older they were more likely to stop or

become more selective about taking medication. The role of the adolescent shifted from passive to active regardless of their involvement to begin with.

Themes that seemed particularly relevant to each paper were also written into memos to aid constant comparison across papers, for example;

- Support for a performance deficit
- Inadequate and inconsistent study skills
- Procrastination
- Absence of goals and plans
- The educational ideal
- From dependence to independence
- Decreased parental involvement
- Increased demands for autonomy
- Self-advocacy
- Social engagement
- Challenges with social relationships
- Benefits of singular pursuit

These were then grouped several ways before the final coding grouping described in the paper. For example,

- Sense of the problem
- Defining ADHD
- Developing autonomy
- Pros and cons of medication
- Receiving support
- Identity
- Stigma

These translated into

- Sense of the problem → Differing perspectives on the problem
- Defining ADHD → Differing perspectives on the problem
- Developing autonomy → Empowerment
- Pros and cons of medication → Feelings about mediation
- Receiving support → Empowerment
- Identity → Sense of self
- Stigma → Societal pressures

Appendix 7

Author guidelines for Clinical Child Psychology and Psychiatry

Clinical Child Psychology and Psychiatry is a peer-reviewed journal that brings together clinically oriented work of the highest distinction from an international and multidisciplinary perspective, offering comprehensive coverage of clinical and treatment issues across the range of treatment modalities.

Writing and submitting your manuscript

Article types. Clinical Child Psychology and Psychiatry is interested in advancing theory, practice and clinical research in the realm of child and adolescent psychology and psychiatry and related disciplines. Articles should not usually exceed 7,500 words and be clearly organized, with a clear hierarchy of headings and subheadings (3 weights maximum). Authors wishing to submit an article longer than 7,500 words should discuss this in advance with the journal editor.

Authorship. All parties who have made a substantive contribution to the article should be listed as authors. Principal authorship, authorship order, and other publication credits should be based on the relative scientific or professional contributions of the individuals involved, regardless of their status. A student is usually listed as principal author on any multiple-authored publication that substantially derives from the student's dissertation or thesis.

Manuscript style

File types. Only electronic files conforming to the journal's guidelines will be accepted. Word DOC is the preferred format for the text and tables of your manuscript.

Journal Style. Clinical Child Psychology and Psychiatry conforms to the SAGE house style.

Reference Style. Clinical Child Psychology and Psychiatry adheres to the APA reference style.

Manuscript Preparation. The text should be double-spaced throughout and with a minimum of 3cm for left and right hand margins and 5cm at head and foot. Text should be standard 10 or 12 point.

Preparation for blind peer review. Wherever possible, authorship should not be revealed or suggested in the manuscript, so as to allow for blind peer review. When citing an author's own work, insert (author citation withheld for peer review) in place of the citation. The citations can be added after a manuscript is accepted for publication.

Your Title, Keywords and Abstracts: Helping readers find your article online. The title, keywords and abstract are key to ensuring readers find your article online through online search engines such as Google. Please refer to the information and guidance on how best to title your article, write your abstract and select your keywords by visiting SAGE's Journal Author Gateway Guidelines on How to Help Readers Find Your Article Online.

Corresponding Author Contact details. Provide full contact details for the corresponding author including email, mailing address and telephone numbers. Academic affiliations are required for all co-authors. These details should be presented separately to the main text of the article to facilitate anonymous peer review.

Guidelines for submitting artwork, figures and other graphics. Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in

colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article. Figures, tables, etc.: should be numbered consecutively, carry descriptive captions and be clearly cited in the text. Keep them separate from the text itself, but indicate an approximate location on the relevant text page. Line diagrams should be presented as camera-ready copy on glossy paper (b/w, unless to be reproduced - by arrangement - in colour) and, if possible, on disk as EPS files (all fonts embedded) or TIFF files, 800 dpi - b/w only. For scanning, photographs should preferably be submitted as clear, glossy, unmounted b/w prints with a good range of contrast or on disk as TIFF files, 300 dpi.

Clinical Child Psychology and Psychiatry does not currently accept supplemental files.

Consent and confidentiality. Disclosure should be kept to a minimum necessary to fulfil the objective of the article. All identifying details should be omitted. For both qualitative and quantitative studies, client or participant consent to participate should be obtained in accordance with ethics committee or institutional approval, and the study information sheets should include advice that the study findings may be published, and that no publications will reveal the identity of individual participants. For case studies, it is essential that the client provides written consent for their case to be published without them being identified, prior to a manuscript being submitted to Clinical Child Psychology and Psychiatry, with a statement to this effect being included in the manuscript text. Any material that is particularly distinctive should be omitted or aggregated. In case reports where ensuring anonymity is impossible, written consent must be obtained from the clients described, or their legal representative, and submitted with the manuscript.

The manuscript must include a statement that confirms that the study is approved by the relevant human ethics research committee, or has institutional approval. Alternatively, for

case studies the manuscript must include a statement confirming the client has provided written consent for their case to be published.

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Declaration of conflicting interests. Within your Journal Contributors Publishing Agreement you will be required to make a certification with respect to a declaration of conflicting interests. It is the policy of Clinical Child Psychology & Psychiatry to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles. Please include any declaration at the end of your manuscript after any acknowledgements and prior to the references, under a heading Declaration of Conflicting Interests. If no declaration is made the following will be printed under this heading in your article: None Declared. Alternatively, you may wish to state that The Author(s) declare(s) that there is no conflict of interest. When making a declaration the disclosure information must be specific and include any financial relationship that all authors of the article has with any sponsoring organization and the for-profit interests the organization represents, and with any for-profit product discussed or implied in the text of the article. Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Declaration of Conflicting Interests provided in the article.

Acknowledgements. Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

All contributors who do not meet the criteria for authorship should be listed in an `Acknowledgements' section. Examples of those who might be acknowledged include a person who provided purely technical help, writing assistance, or a department chair who provided only general support. Authors should disclose whether they had any writing assistance and identify the entity that paid for this assistance.

Funding Acknowledgement. To comply with the guidance for Research Funders, Authors and Publishers issued by the Research Information Network (RIN), **Clinical Child Psychology and Psychiatry** additionally requires all Authors to acknowledge their funding in a consistent fashion under a separate heading.

Appendix 8

Ethical approval

Health Research Authority
National Research Ethics Service

North West - Lancaster Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Telephone: 020 71048008

08 January 2016

Dr Laura Soulsby
Lecturer in Psychology
University of Liverpool
School of Psychology, University of Liverpool
Eleanor Rathbone Building
Bedford Street South
L69 7ZA

Dear Dr Soulsby

Study title:	**A qualitative study into the impact of an ADHD diagnosis upon self-identity and personal relationships in adolescents**
REC reference:	**15/NW/0946**
Protocol number:	**UoL001164**
IRAS project ID:	**189174**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Carol Ebenezer, nrescommittee.northwest-lancaster@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Advert]	1	15 November 2015
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Cover University of Liverpool]		05 September 2015
Interview schedules or topic guides for participants [Interview schedule]	1	15 November 2015
Letter from sponsor [Sponsorship approval LHP]		10 November 2015
Letters of invitation to participant [Letter to participants]	2	03 January 2016
Non-validated questionnaire [Demographic questionnaire]	1	15 November 2015
Other [Clarification re 3rd paragraph A13]	E-mail	24 November 2015
Other [Example text message]	2	03 January 2016
Participant consent form [Consent form]	1	15 November 2015
Participant consent form [Consent form]	2	03 January 2016
Participant information sheet (PIS) [Staff information sheets]	1	09 November 2015
Participant information sheet (PIS) [Participant information sheet]	2	03 January 2016
REC Application Form [REC_Form_23112015]	5.1.0	20 November 2015
Referee's report or other scientific critique report [Research review committee approval University of Liverpool]		22 June 2015
Research protocol or project proposal [Research proposal]	3	23 October 2015
Summary CV for Chief Investigator (CI) [Laura Soulsby CV]		
Summary CV for student [Laura Eccleston CV]		20 November 2015

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

15/NW/0946	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Dr Lisa Booth
Chair

Email:nrescommittee.northwest-lancaster@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Alex Astor, University of Liverpool*
Mrs Alison Loftus, Bolton NHS Foundation Trust

Health Research Authority

North West - Lancaster Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

20 May 2016

Dr Laura Soulsby
Lecturer in Psychology
University of Liverpool
School of Psychology, University of Liverpool
Eleanor Rathbone Building
Bedford Street South
L69 7ZA

Dear Dr Soulsby

Study title:	**A qualitative study into the impact of an ADHD diagnosis upon self-identity and personal relationships in adolescents**
REC reference:	**15/NW/0946**
Protocol number:	**UoL001164**
Amendment number:	**1**
Amendment date:	**13 May 2016**
IRAS project ID:	**189174**

Change to inclusion criteria and recruitment

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The members had no ethical issues with this amendment.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Copies of advertisement materials for research participants	2	25 April 2016
Non-validated questionnaire [Demographic]	2	25 April 2016
Notice of Substantial Amendment (non-CTIMP)	1	13 May 2016
Other [social media]	1	25 April 2016
Other [letter to participants non clinical]	1	25 April 2016
Other [letter to participants]	3	25 April 2016
Participant information sheet (PIS) [participants]	3	25 April 2016

Participant information sheet (PIS) [staff]	2	25 April 2016
Research protocol or project proposal	4	25 April 2016

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

15/NW/0946:	**Please quote this number on all correspondence**

Yours sincerely

Dr Lisa Booth
Chair

E-mail: nrescommittee.northwest-lancaster@nhs.net

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Mrs Alison Loftus, Bolton NHS Foundation Trust*
Alex Astor, University of Liverpool

NHS
Health Research Authority

Dr Laura Soulsby
Lecturer in Psychology
University of Liverpool
School of Psychology, University of Liverpool
Eleanor Rathbone Building
Bedford Street South
L69 7ZA

Email: hra.approval@nhs.net

16 August 2016

Dear Dr Soulsby

Letter of HRA Approval for a study processed through pre-HRA Approval systems

Study title:	**A qualitative study into the impact of an ADHD diagnosis upon self-identity and personal relationships in adolescents**
IRAS project ID:	**189174**
Sponsor	**University of Liverpool**

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **HRA Approval.** This has been issued on the basis of an existing assessment of regulatory compliance, which has confirmed that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).

Participation of NHS Organisations in England

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with HRA Approval Processes. It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate Statement of Activities and HRA Schedule of Events. The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study. If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA..

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

After HRA Approval

In addition to the document, *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the HRA website.

Your IRAS project ID is 189174. Please quote this on all correspondence.

Yours sincerely

Elizabeth Bottomley
Application Administrator

Email: hra.approval@nhs.net

Copy to: *Alex Astor, University of Liverpool*
Mrs Alison Loftus, Bolton NHS Foundation Trust

Appendix 9

Advert

Version 25.04.16

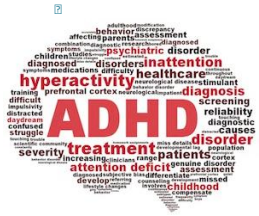
UNIVERSITY OF LIVERPOOL

Royal Bolton Hospital NHS
NHS Foundation Trust

Alder Hey Children's NHS
NHS Foundation Trust

Pennine Care NHS
NHS Foundation Trust

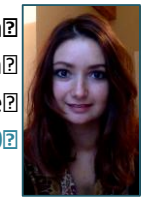
Do you have a diagnosis of ADHD?



We are interested in **your experiences** of getting this diagnosis and how it has affected **you** – the way you **see yourself,** the way other people **see you, your relationships.**

- Are you 16 – 18 years old?
- Were you diagnosed with ADHD when you were aged between 8 – 13 years old?
- Would you be happy to talk about your experiences for one-hour as part of a research study?

If you would like to hear more information then **please contact Laura Eccleston** by telephone or email, or ask your key worker to get in touch with her for you. She will phone and arrange to meet with you to give you some more information. If you take part, you would receive a **£10 voucher** in return for your time.



Don't worry, this doesn't mean you have to take part – you can change your mind at any time. We keep everything you say confidential so people will not be able to identify you from the information you provide.

This study has been approved by the NHS Research Ethics Committee.

Laura Eccleston
l.eccleston@liverpool.ac.uk
07495067708

Laura Eccleston
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Appendix 10

Participant information sheet

Participant Information Sheet

Research Study: The effect of an ADHD diagnosis upon self-identity and personal relationships in adolescents

We would like to invite you to take part in our research study. Before you decide whether or not you would like to take part, we would like to explain why the research is important and what it would involve for you. One of the researchers will go through the information sheet with you and answer any questions you have. Please ask if there is anything that is not clear.

What is the purpose of the study?

This study aims to look at people's experiences following their ADHD diagnosis. It hopes to gain a better understanding of how this diagnosis or label impacts upon what people think about themselves, what other people think about them, and how other people act around them. It is hoped that findings from this research will help to guide future interventions and support for children before, during and after the time that they are diagnosed with ADHD.

Why have I been invited?

You have been invited because you were diagnosed with ADHD when you were aged between **8 and 13 years old**. We are only interviewing people aged between 16 and 18 at the time of the interview.

Do I have to take part?

No – it is your decision entirely. If you decide to take part, you will be asked to sign a consent form and you are free to withdraw at any time without giving a reason. If

you decide to withdraw from the study, you can have the data you provide destroyed. Withdrawing from the study would not affect the care you receive from the team in any way. You will not have to answer any questions that you do not want to answer.

What will happen to me if I take part and what will I have to do?

You will be asked to meet with Laura Eccleston, the lead researcher, for a one-off meeting either at your local clinic or at your preferred location (this could be your local library or health centre). These meetings will take place in a quiet and confidential space. We expect meetings to last around 1 hour and there will be opportunities to take breaks at any time if needed. At the meeting you will be asked to answer a few questions describing your experiences before, during and after your ADHD diagnosis was made. Laura will be available to answer any questions you have. We will audio record the interview and then it will be transcribed. Any identifying information will be removed. We need around 20 people to take part, so if more than 20 people volunteer you might not be interviewed.

If you take part in the study you will be reimbursed for your time with a £10 High Street voucher, which can be spent at 20,000 stores including River Island, New Look, HMV, Argos, Boots, Debenhams, Toys 'R' Us, House of Fraser, Waterstones and WH Smith.

What are the possible risks of taking part?

There is little risk involved in taking part in the study. However, some people may find it difficult or upsetting to answer some questions on their experiences. This distress is normal and the researcher will be trained to deal with this sensitively. The researchers will have contact numbers for organisations that may be able to provide extra support. The interview is intended to end on a positive note. Participants are welcome to contact the researchers after the interview if they have any further questions.

What are the possible benefits of taking part?

Although there are no direct benefits to taking part in the study, the information we collect will help improve people's understanding of how an ADHD diagnosis affects a person's identity and relationships and could help to develop new ways of supporting children who may be diagnosed with ADHD in the future.

What about confidentiality?

No information will be passed onto any other person without your permission. The only exception will be if there is a direct risk of harm to you or another person. In these cases it may be necessary to talk to another health professional, such as a GP or therapist. If this happens normally it would be discussed with you first.

All information collected about you during the study will be kept confidential, and any identifying information about you (e.g. your name or address) address will be removed so that you cannot be recognised. You will not be named or identified in any reports of the study. We would like to be able to use quotations from your interview but we will change any identifying features. However, you can also decide to take part but ask us not to use direct quotations if you wish.

All data collected from the study will be kept safely and securely on a password protected computer. Laura Eccleston and Dr Laura Soulsby (supervising this study) will be the custodians of all the study data. With your permission, the data will be archived and stored at the University of Liverpool for 10 years after the end of this study. Your consent form will be stored separately from these materials.

What happens when the research study stops?

When you have completed the interview, you will not be asked to do anything else.

The findings will be written up as part of the researcher's thesis, which forms part of their doctoral training as a Clinical Psychologist. The researchers hope to publish papers in academic journals and to present the findings at conferences. All your information will be anonymised in these reports so you will not be identifiable. Please write on the consent from if you would like to receive a feedback report describing the results of the research when the study has finished. You can request copies of any reports made if you wish.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions. If you remain unhappy or have a complaint, then you should contact the Research Governance Officer at the University of Liverpool - ethics@liv.ac.uk or 0151 794 8290. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researchers involved, and the details of the complaint you wish to make.

Who is organising and funding the study?

The University of Liverpool have provided the funds to carry out this study and the University of Liverpool is the study sponsor.

Who has reviewed the study?

This study was given a favourable ethical opinion for conduct in the NHS and other sectors by the Doctorate in Clinical Psychology Research Ethics Committee.

Who can I contact for further information this study?

If you have any questions at all, at any time please contact the researchers:

Laura Eccleston	Lead researcher (University of Liverpool)	l.eccleston@liverpool.ac.uk
Laura Soulsby	Supervisor (University of Liverpool)	l.k.soulsby@liverpool.ac.uk
Sue Knowles	Supervisor (Greater Manchester West)	Sue.knowles@gmw.nhs.uk
Mark Bowers	Supervisor (Royal Bolton Hospital)	Mark.bowers@boltonft.nhs.uk

Who can I contact for more general information about taking part in research?

If you would like more general information about taking part in research, please contact Karen Wilding at the University of Liverpool on 0151 794 8373 or kwilding@liverpool.ac.uk who is independent from this study.

Thank you very much for taking time to read this information sheet.

Appendix 11

Consent form

CONSENT FORM

Title of Project: A qualitative study into the impact of an ADHD diagnosis upon self-identity and personal relationships in adolescents

Name of Researcher: Laura Eccleston

Participant Identification Number:

		Please initial in the box
1	I confirm that I have read and understand the information sheet dated..... (version.....) for the above study. I have had the chance to think about the information, ask questions and have my questions answered.	
2	I understand that taking part is voluntary and that I can change my mind at any time without giving any reason, without my medical care or legal rights being affected.	
3	I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Liverpool, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4	I understand and agree to the interview being audio recorded	
5	I agree to take part in the above study	
6	I would like to receive a summary of the findings at the end of study	

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes

Version 2, 03.01.16

1

Appendix 12

Demographic questionnaire

Demographic Questionnaire
Version 2, 25.04.16

We would like to learn a little bit more about you. Remember, you do not have to answer anything you do not want to. Any answers you provide will not be traced back to you and your name will not be on this document.

Participant Number:

Date of birth (MMYY): Age:

Gender: ☐ Male ☐ Female ☐ Other

Ethnicity: ☐ White British ☐ Black or Black British ☐ Asian or Asian British ☐ Mixed or multiple ☐ Other

Diagnoses:

Age diagnosed with ADHD:

Where did you live when you were growing up?

_____

If your parents or carers worked, what job(s) did they have?

Appendix 13

Reflexive statement

I often wondered how being diagnosed with a mental health problem affected children and young people. This interest stemmed from my clinical work as an Assistant Psychologist working with children who had lived through extremely damaging early life experiences such as physical, emotional or sexual abuse and neglect or had insecure attachment styles. Frequently these children had been labelled with a range of diagnoses, which often changed over time but included "autism", "ADHD", and "conduct disorder". These children also tended to be labelled as "naughty", "disruptive", "liars" and "attention seeking". I was curious about the process involved in making each of these diagnoses, which often appeared to neglect the social context of the child's home environment (thereby invalidating their experience). I was also curious as to how much of these labels the child internalised, at an age where they were developing their sense of identity and whether receiving a diagnosis affected that identity. I wondered how the diagnosis changed their relationships with their parents (who often pushed for a diagnosis), their teachers and their peers. Finally I wondered what made the outcome of receiving a diagnosis helpful or unhelpful.

As a Trainee Clinical Psychologist, I am interested in supporting children in their development of a positive sense of self and the formation of strong positive relationships with significant people in their system. I would like services to have a better understanding of helpful and unhelpful ways of intervening in these situations, whether through diagnosis or not. I would like children to have a positive experience of mental health services (and other relevant services e.g. school), meaning they may be more likely to utilise these services for support. I wish to alleviate distress and promote strengths and resource for their future. In essence, I strongly believe in 'early intervention' and supporting children in the best way possible upon their first presentation to services. I would like to know how we could do things differently; how we could do things better.

I come from a position whereby I appreciate that labelling someone categorises them and will have consequences for their identity and relationships with others. I favour a formulation-based approach to working with people's difficulties and distress. I think this issue is particularly pertinent for children, who have not yet established their sense of self.

However, I believe that some children may find the diagnostic experience validating; where they have previously been labelled in a derogatory way, having a 'reason' for their behaviour may be reassuring. Some children may have found medication helpful. I think this might depend upon the way the child has been involved in the diagnostic process, other people's narratives surrounding diagnosis (e.g. whether teachers, parents, siblings, peers agree and are understanding or who disagree and are dismissing, critical) and the explanations they give for their behaviour prior to the diagnosis being made.

Overall I believe children will have positive and negative experiences surrounding diagnosis and the impact this has had upon their identity and relationships. I am interested in what factors affect these differing outcomes.

Appendix 14

Interview schedule 1, dated 15/11/2015

1. **What was life like before you got a diagnosis of ADHD?**

   How would you describe yourself? What words would you use?

   What was it like at school? How were your relationships with your friends?

   What was it like at home? Who was there at that time? (Use the circles to explore relationships). How were your relationships with your mum, dad, siblings, anyone else that was important?

   How do you think other people would have described you?

   What were your main challenges? How did you explain these?

   What was going well? What were you good at?

2. **What was it like to get a diagnosis of ADHD?**

   Can you remember why you first accessed CAMHS? What kind of difficulties were you having?

   How old were you when you got a diagnosis of ADHD? What happened?

   How did it make you feel? What did it make you think? (what was good / not good / how did you cope?)

   What was your understanding of what ADHD is? What is your understanding now i.e. has it changed?

   Did you speak to anyone about it? What did they think?

   What could have been better?

3. **How have things been since you were diagnosed?**

   (How) did getting a diagnosis of ADHD change what you thought about yourself?

   What words would you use to describe yourself now?

   How did you think it changed what other people thought about you (family, friends, teachers).

   How do you think that the ADHD affects you now?

   What were the biggest changes in your life that you have noticed since your diagnosis? (relationships, did it change what you did with your time, school, support, good parts, not so good parts)

   What kind of support did you get? (emotional, practical, financial, what was helpful, at home and school), where did you get it from?

   As time went on what have been the main difficulties and challenges you have noticed? (How did you cope with these difficulties?)

4. **Concluding questions**

   What support would you have liked more of?

   Are there things you haven't spoke about yet that would be interesting to tell me or that I might like to know?

   If you could give advice to somebody who had just got their diagnosis, what would you tell them?

Appendix 15

Interview schedule 2, dated 10/02/2017

1. Has getting a diagnosis of ADHD changed you?
    i. What you thought about yourself?
    ii. Your understanding of what was going on for you?
    iii. What other people thought about you?
    iv. Coping with emotions?
    v. Whether or not you fit in? Or feel different?

2. Did it change you positively or negatively?

3. Did you get…
    i. Medication (what?)
    ii. Support (what?)

4. If you have changed how much is due to diagnosis, medication, support?
    i. How did each of these change you?

5. Have you changed as a person since you were younger?
    i. How? What helped? Any big life events?
    ii. For better? For worse?
    iii. What would other people say?

6. How much of this change is due to you 'growing up' or things things that would have happened anyway?
    i. E.g. friends, where you're living, school etc?

7. What has been most or least helpful for you?
    i. Diagnosis
    ii. Medication
    iii. Support
    iv. Growing up

8. Do you think ADHD fit with how you saw yourself before you got a diagnosis?
    i. What did you think about ADHD before? After? Did that change? How?

Be thinking about

- *Personal agency/ self-control*
- *Self awareness*
- *Reflective function / awareness of consequences*
- *Emotion regulation / coping*
- *Acceptance / rejection of dx and thoughts about ADHD*

Appendix 16

Example of memo for interview 5

Summary of narrative

Prior to getting a diagnosis of ADHD, Sian described "knowing something was wrong" with her and "feeling different". She was "not concentrating", "fidgeting" and being "hyperactive", meaning that her "pre-existing identity 'fit' with ADHD descriptions".

She also described "being unable to meet expectations", "wanting to be liked" and "trying to fit in" but feeling like she was "getting it wrong" and being "paranoid" and 'anxious' about this and what other people thought about her, so she was constantly "questioning self". She identified as someone that "needed more support" and "had different needs" and said she "didn't get support before diagnosis".

She described "feeling misunderstood" with other people thinking she was "a bad kid" and this was "a vicious cycle", because the arguing increased the behaviour which made people think worse of her, which increased the arguing and behaviour – until "it was all bad". Thus there was a "mismatch between self-self identity and other-self identity", which meant that she was "lacking control" and "lacking understanding of self".

She had "no prior awareness of ADHD" and therefore had no particular thoughts about it. She did not have any particular recollections regarding assessment but "felt involved" and "heard" and felt like she "needed a solution". She remembered "hearing others' perspectives" made her "discover her inner wrongness", which made her "feel scared" and "worry about the future" as well as "increasing self-frustration". She subsequently "actively learned about ADHD", which facilitated her understanding. Because her "pre-existing-identity 'fit' with ADHD description, she adopted 'ADHD' as a description of self. This aided her understanding not just of her diagnosis, but her "understanding of herself". She also described, "feeling more understood after diagnosis" but "feeling frustrated at the extra hurdle". There was also something about the diagnosis "legitimising negative aspects of self".

Sian mostly described how "getting a diagnosis lead to support" and she attended an ADHD group, which she found really helpful at "increasing self-awareness", "increasing coping resources" through "talking to others" and "discussing problems". There was some support in school that aimed at "increasing self-reflection", "increasing self-awareness" and "increasing awareness of consequences", which was "distressing but helpful for future" and seen as "a learning process" and "empowering". She said she "loved the support" and "feeling heard and accepted". Sian was able to reflect on the reasons for her previous behaviour, "wanting to fit in with the wrong people" and "be the class clown", and how, over time, she had "shifted her values"; she had got older, left school and "my minds just clicked". From

her descriptions it sounded as though “maturation was a process of learning”. As Sian eloquently put it – “developing conscience”.

However, there were limits to this support. She felt that she “needed more school support” and teachers instead viewed the ADHD as “imposing limits on self”, rather than “finding ways to maximise potential” and “needing someone to talk to”. She felt that she had “never really got help at all with academic work”. This changed in college, where there were “less restrictions” on what she could do, which “increased coping resources” such as listening to music in lessons. It sounded like getting academic support (being listened to and helped) had really helped **shift identity from “a problem” to “person with a problem”.**

Sian described “having high expectations of medication” which were “dashed” when she found that “medication did not help” and actually she noticed a “worsening on medication” reporting lots of side effects. Like others, she described the “specificity of medication” was often altered by that “mediation never worked”. To cope with the expectation that she would take medication, Sian began “hiding her medication” from others. When she was aged 14 she reported, “choosing to stop medication”. This sounded like it was because “medication makes me ‘not me’”. As though “medication had changed personality/identity”. So her “feelings of self on medication” changed, and this had a negative effect on her identity.

Sian described that move away from school and her old friends, unsupportive teachers, and restrictions and expectations that she could not meet, “changed my head” and “made me mind just click”. Thus there is something about the social context maintaining the problem for her and this sense of self as the one to blame and the problem. She described how she still has the same problems but the support and reduced criticism helps her to “feel better about it…then that gets you through it”.

Sian highlighted one important aspect – that she “finds it difficult to seek support” and at the time also found it “difficult to utilise support” that was offered. “Feeling misunderstood” had lead her not to trust others.

<u>Critique of questioning style</u>

Towards the end of the interview, I ought to have ended. I recognised that Sian was becoming tired and I had gained so much information from her. Some of the final questions were repetitions of old ground and were unnecessary. I was pleased however that in the beginning parts of the interview, I was able to stay with certain topics until I felt all that there was to be gained was explored with Sian. It would have been easy to avoid lingering on topics, particularly where she did not understand the question, but rephrasing, repetition and sticking with it, really helped gain all there was to gain from the interview. I felt like overall this was a good interview. The only thing that I would change in future interviews would be to focus on the hypotheses and testing these hypotheses within my questions slightly more. Sometimes this interview resembled the first 4.

Hypotheses

Pre-existing self-identity affects assimilation of ADHD diagnosis into identity

- If ADHD matches sense of self = integrated
- If see prior self as "a problem" = integrated
- If see prior self and behaviour as normal = not integrated
- Sense of 'normality' depends on context

Diagnosis

- increases understanding of self
- increases others understanding and compassion
- leads to support

Medication alters sense of who I am and coping (can be positive or negative)

- Positive if sense of self remains same but decreases negative aspects – "becoming a better version of self"
- Negative if sense of self changes and no positives identified but positive aspects are decreased

Support is helpful where needed

- Increases self awareness
- Increases self-reflection
- Increases awareness of consequences/ empathy/ others' perspectives
- Empowering

Maturation results in

- Shifting values and perspectives
- Learning process
- Self-confidence

Combined, these factors increase coping resources

- Escaping the vicious cycle
- Leads to belonging, acceptance and better support network

This leads to a shifting identity from 'a problem' to 'a person with a problem'

Future questions

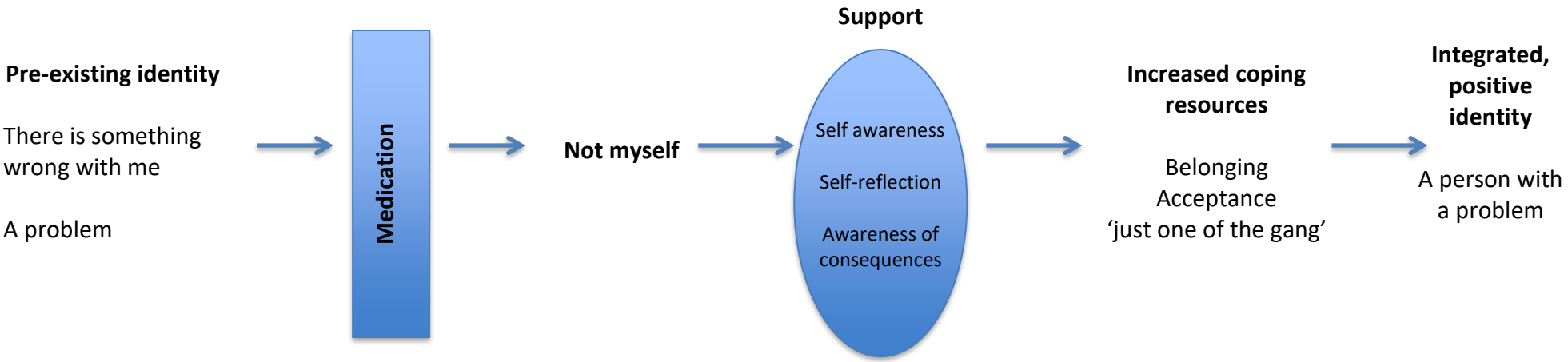
What does medication do that is different to support / growing up? Medication only seems to have helped interviewed participants several years later, how do they explain this as being medication and not support/growing up?
How does this all fit to identity, what did they think about themselves at different points? Did they like themselves/not like themselves?
Need to go back to the literature – what do we know about identity already? What do we know about identity's after mental health diagnoses? Can this inform our thinking?
Can we fine tune the descriptions of self through these stages so 'a problem' → ? disabled → ? just a normal adolescent (or something else) →to a person with a problem? Are there other stages and we can then show what is involved in each of these stage shifts?
Feels like the focus of the analysis needs to start shifting onto identity, at each of these points what did they think about themselves, how did the diagnosis the

medication, growing up shift what they thought about themselves, did they think they were normal? Disabled? Where they liked? Liked themselves? What role did they take on?
Something about all participants 'wanting to help or please others' – they have all been very clear that taking part in research is to help me – this has cropped up in interviews too e.g. identity as a 'protector' or 'defender' or 'the class clown'…is there more to this?

Identity descriptions

- The class clown
- Defender
- Protector
- Normal young girl
- Different and weird
- Bad kid
- A problem
- A person with a problem
- Disabled

Anything else?


Pre-existing identity
There is something wrong with me
A problem
Medication
Not myself
Support
Self awareness
Self-reflection
Awareness of consequences
Increased coping resources
Belonging
Acceptance
'just one of the gang'
Integrated, positive identity
A person with a problem

Appendix 17

Memo: The radio talk show

Memo 14b after 5 interviews – the radio talk show

So far we have done six interviews and the findings have been really interesting.

The young people seemed to have gained a sense of who they were from a young age, meaning that by the time they got a diagnosis of ADHD when they were aged 8-13 they already had an idea of their self-identity, whether or not they liked themselves and whether or not other people liked them. This seemed an important factor in considering how their identity formation was affected by getting an ADHD diagnosis. Most of our participants described their former selves in ways that 'fit' with ADHD, such as 'hyperactive', 'impulsive', and 'fidgety', and some recognised that this made them behave in ways that were deemed 'naughty' or that meant they were 'the class clown'. Most felt 'different' and like they were 'unable to meet expectations', which tended to relate to expectations set by school. However others did not feel like these descriptions fit them and felt that ADHD was quite alien to their experience of themselves. All described struggling with their emotional regulation (often in consequence to their perceived failures), which made them feel as though they lacked control over their actions. They felt they received no support to help with this but instead were penalised for their own manner of coping (e.g. leaving the room to calm down or distracting themselves), which often led to an escalation of behaviours and served as a viscous cycle. Some young people recognised that they were having a problem for which they were not getting support, and therefore wanted to find a solution. Some didn't and instead considered their behaviour normal and unproblematic. However, most of them reported liking themselves and having positive peer relationships even if their relationships with teachers and parents were more strained.

The adolescents we interviewed had varying understandings of ADHD both before diagnosis and following it. Their own personal understanding of ADHD and how it fit with their existing understanding of self appeared integral to whether the diagnosis was accepted or rejected as part of the person's identity. These young people found that getting a diagnosis was a process of discovering inner wrongness; a previously unidentified flaw within themselves, or confirmation of a pre-conceived flaw. All participants were immediately offered medication by professionals, which led those that thought they were 'normal' to question why they needed a drug to do what they ought to be able to do themselves (i.e. control themselves), or why they needed to change when nothing was wrong. Thus in these cases the medication acted to pathologise their distress or behaviour, and caused further distress and withdrawal from others/life. Others took the medication without question, and those that had previously identified a problem considered it something of a 'cure'.

The medication journey was described as being difficult for all of the adolescents we interviewed, being a process of finding the *right* medication, the one that helped them concentrate better, without causing too many side effects. None of the participants wanted to change themselves, yet the medication created a 'different version of self',

which was not always deemed a positive transformation. Sometimes this left the young people feeling too altered and stripped of their positive attributes (e.g. energy and enthusiasm) instead feeling like ‘a zombie’. Others viewed their hyperactivity as a negative quality and were grateful for it being reduced by the medication.

Where ADHD fit with the persons pre-existing sense of self, the diagnosis and medication themselves did not always lead to any change in understanding of the situation or perspectives (initially at least), and participants described several years between diagnosis and any identification of change. In this time there might have been a period of denial or avoidance, whereby the young person acted to hide the diagnosis from others and continued to act within the differing norms provided by their aligned social context. Identity shifts here seemed to occur following a change in situation (such as moving schools or going to college) or a significant life event (such as contact with the police or more serious hard crime), which led to shifting values and perspectives and made a redefinition of self more possible.

We interviewed participants across several services, which meant the support the young people received varied widely. However a consistent theme was that participants found it helpful to have someone to talk to who really listened to them and did not dismiss them or invalidate their distress because of their behaviour. This helped them to feel valued, supported and ‘normal’. Where the agent of change was deemed to be the medication, the young person did not particularly feel a need to change and therefore rejected this support, since they did not feel it was needed. Instead the young person appeared to have developed skills regarding self-awareness and reflective function via a process of shifting perspectives, life experience and maturity, alongside the maturation of their peer group or changing context. However, for young people that had a less secure sense of self and described feeling more anxious about fitting in and relationships, having a space to reflect on this appeared invaluable in facilitating exploration of ‘another way of doing things’.

To conclude, a process of maturation and life experience naturally increased the young people’s reflective function, resilience, coping, and self-awareness, underpinned all of the young people’s identity shifts over time. Their pre-diagnosis experience and current context both affected their identity transitions and the appraisals of these transitions following the stages of diagnosis, medication and support.

Appendix 18

Coding Matrix

	1	2	3	4	5	6	7	8	9	10	11
Prior experience	Normal Protector	Normal	Class clown Protector	Normal Protector	Class clown	Normal Class clown Protector	Protector	Normal Protector	Normal Protector	Normal Protector	Normal Class clown Protector
View of ADHD	Normal	Disability	Normal	Normal	Disability	Normal	Disability	Normal	Normal	Normal	Normal
Impact of dx	Unfazed	Negative	Unfazed	Positive	Positive	Positive	Negative	Unfazed	Unfazed	Unfazed	Unfazed
Questioning self	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Discovering inner wrongness	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
ADHD kid	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Identity fit	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Stigma	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Support offered	Minimal	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Yes (school)
Helpfulness of support	Neutral	Yes	No?	Yes	Yes	Yes	No	N/A	Yes	Yes	Yes
Side effects	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Altered by meds	Good (after maturing)	Good	Neutral	Good (after maturing)	Bad	Bad	Bad	Dependin g on context (after maturing)	Neutral	Good (after maturing) but no longer needed	Bad
Choice / autonomy	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Moment of realisation	Yes	No	No	Yes	Yes	Yes	No	Yes	No	Yes	No
Shifting values	Yes	No	No	Yes	Yes	Yes	No	Yes	No	Yes	No
Self development	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Problem → person with problem	Yes	No	No	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
Meaning and purpose	Yes	No	No	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Recognition of strengths	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Current stage	Satisfied	Self-development	Dx and meds	Satisfied	Satisfied	Satisfied	Side effects	Satisfied	Maturing	Satisfied	Satisfied

Appendix 19

Mapping focussed codes onto theoretical codes

Focussed codes	Theoretical codes
Prior experience	**Pre-existing sense of self (includes bullying and rejection)**
A vicious cycle	
Befriending allies	
Being a burden	
Being a square peg in a round hole	
Being or feeling rejected	
Being punished	
Coping with distress	
Doing what is 'right'	
Experiencing cognitive dissonance	
Feeling misunderstood/not understood	
Feelings and emotions	
Fight or flight	
Having close family relationships	
Having different rules and norms	
Lacking choice and control	
Lacking coping strategies	
Lacking empathy	
Lacking peer relationships	
Lacking support	
Lacking understanding of self	
Losing control	
Making attributions	
Mismatch between other-self and self-self identity	
Needing a solution	
Needing support	
Not recognising consequences	
Other-descriptions	
Prioritising self	
Recognising consequences	
Seeing advantages to behaviour	
Self appraisal	
Self-descriptions	
Sense of the problem	
Sibling rivalry	
Struggling to articulate needs/feelings	
Symptoms dependent on context	
Taking out feelings on others	
Trying to please others or fit in	
Using aggression as a tool	
Using available resources	
Viewing symptoms as positive aspects of self	
Experience of assessment	**Excluded from final model due to lack of relevance**
Feelings about assessment	

Getting a solution	
Going through the motions	
Hearing other perspectives	
Involvement	
Impact of diagnosis	**Reframing self within construct of ADHD**
Reflecting on 'fit' with prior identity	
Absolving self-responsibility	
Assimilating other-descriptions	
Avoiding thinking about it	
Becoming depressed	
Becoming 'the ADHD Kid'	
Being unfazed	
Discovering inner wrongness	
Distinguishing between self and behaviour	
Acknowledging impact on others	
Expecting negative future	
Externalising	
Feeling normal despite diagnosis	
Feelings following diagnosis	
Helpfulness of getting diagnosis	
Increased understanding of self	
Made people want to help	
Pathologising distress	
Pathologising perceived 'normality'	
Perceiving others' low epectations	
Recognising self despite diagnosis	
Recognition of problem	
Redefining self	
Reducing self-worth	
Shifting blame	
Shifting from normal to abnormal	
Shifting identity	
Shifting sense of normal	
Withdrawing from others	
Worrying about the future	
Worrying about what is wrong with me	
Taking medication	**Redefining self on medication (includes side effects)**
Becoming a different 'me'	
Becoming autonomous	
Effectiveness	
Having side effects	
Searching for the 'right' tablets	
Thoughts about medication	
Varying dosage	
Thoughts about ADHD	**Personal meaning of ADHD**
A 'real thing' – condition or disability	
Academic problem	
Lacking understanding	
Limiting	
Naughty	
Normal – like hayfever	

Stigma	**Stigma**
A viscious cycle	
Being rejected or isolated	
Difficulty seeking support	
Experiencing others as insensitive	
Fearing rejection and judgement	
Feeling different	
Feeling humiliated or exposed	
Hiding diagnosis or medication	
Provision of support	**Support**
Coping contingent on support	
Enabling maturation	
Enjoying support	
Feeling criticised	
Feeling heard and accepted	
Feeling listened to	
Feeling supported	
Feeling understood	
Feeling unsupported	
Friendships	
Helpfulness of support	
Increasing coping and resources	
Increasing reflective function	
Increasing self-awareness	
Needing someone to talk to	
Needing support	
Normalising	
Personal agency presumed	
Recognising different needs	
Reducing support	
Rejecting support	
Support as a learning process	
Support got me through it	
Support not needed or rejected	
Talking helpful	
Using distraction	
Maturation	**Maturation**
Assimilating parental values	
Changing identity over time	
Considering consequences	
Embracing difference	
Experiencing moment of realisation	
Gaining meaning and purpose	
Gaining quality friendships	
Increasing sense of self	
Increasing tolerance	
Learning from others	
Listening to guidance	
Maturing as a learning process	
Maturing leads to identity shift	
Maturing leads to self-development	
Maturing alongside peers	

Maturing creates stronger bonds	
Re-evaluating goals and values	
Realising personal agency	
Recognising previous destructive path	
Resolving difficulties	
Retaining aspects of prior self	
Seeing alternatives	
Settling down	
Shifting values and perspectives	
Understanding increases coping	
Wanting to change	
Self development	**Self-development**
Conforming and complying	
Considering consequences	
Continuing existence of the problem	
Developing better coping strategies	
Developing empathy	
Developing resilience	
Developing conscience	
Becoming a better version of self	
Gaining control	
Improving relationships	
Increasing self-awareness	
Increasing sense of personal agency	
Self reflection	
Acceptance, empowerment, autonomy	**Satisfaction with self-identity**
Acceptance not dependent on medication	
Accepting diagnosis	
Accepting identity	
Being accepted	
Belonging or fitting in	
Changing self-appraisals	
Congruency of ADHD and prior identity	
ADHD as part of self	
Distinction between self and behaviour	
Embracing difference	
Developing sense of belonging	
Feeling different and rejected	
Feeling excluded and isolated	
Feeling not understood	
Shifting views of ADHD	
Legitimising negative aspects of self	
Recognising there was a problem	
Shifting prom a problem to a person with a problem	
Shifting social context	
Understanding aids acceptance	
Values and identity maintained despite diagnosis	